UNIVERSITY OF WINCHESTER

The Ethics of Solid Organ Donation and Transplantation: An Alternative View

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This thesis has been completed as a requirement for
a postgraduate research degree of the University of Winchester

A human being is a part of the whole called by us universe, a part limited in time and space. He experiences himself, his thoughts and feelings as something separated from the rest, a kind of optical delusion of his consciousness. This delusion is a kind of prison for us, restricting us to our personal desires and to affection for a few persons nearest to us. Our task must be to free ourselves from this prison by widening our circle of compassion to embrace all living creatures and the whole of nature in its beauty.

Albert Einstein

For

The wonderful-ness of be(com)ing together

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Abstract:

Current bioethical frameworks supporting the Western medical model are criticised for failing to offer appropriate guidance to doctors in a climate of increasingly complex medical decision-making - an ethically demanding situation that renders bioethical guidelines both contested and problematic. The Principlist bioethical framework of choice for numerous medical institutions globally comprising the four principles of autonomy, beneficence, non-maleficence and justice is deemed too high-level, reductionist, static and out-dated. Considered a universal model that covers all bioethical eventualities by the developers Tom Beauchamp and James Childress, the framework fails to give human embodiment its significance at a time when medical technologies are advancing apace, but gives preference to rational and intellectual control over medical matters rather than valuing affective or embodied states. Organ donation and transplantation has been chosen as a research field to mount a robust challenge to Principlism and other alternative bioethical models. Being both emotionally sensitive and physically demanding on donors and recipients, transplantation medicine sits at the extreme limit of ethical acceptability. That biotechnology has progressed to the point where the traditional meaning of the body is brought into question is critical. The case for arguing the body from a perspective that reads it as wholistic, meaningful, relational and continually in a state of flux has implications for the future of medicine and any attendant ethical support. It requires a radical departure from a dualist interpretation of the repairable body, to one that places the relief of suffering at the forefront of patient care. Patient narrative is considered helpful in foregrounding individual care and the need for co-operative decision-making. It strengthens a flexible approach to bioethics capable of adapting to future sophisticated developments in medicine; it ensures inclusivity and multi-vocality, and allows for the creation of ethical norms and values worthy of the complexity of our times.

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Declaration

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Abstract

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Current bioethical frameworks supporting the Western medical model are criticised for failing to offer appropriate guidance to doctors in a climate of increasingly complex medical decision-making - an ethically demanding situation that renders bioethical guidelines both contested and problematic. The Principlist bioethical framework of choice for numerous medical institutions globally comprising the four principles of autonomy, beneficence, non-maleficence and justice is deemed too high-level, reductionist, static and out-dated. Considered a universal model that covers all bioethical eventualities by the developers Tom Beauchamp and James Childress,[1] the framework fails to give human embodiment its significance at a time when medical technologies are advancing apace, but gives preference to rational and intellectual control over medical matters rather than valuing affective or embodied states. Organ donation and transplantation has been chosen as a research field to mount a robust challenge to Principlism and other alternative bioethical models. Being both emotionally sensitive and physically demanding on donors and recipients, transplantation medicine sits at the extreme limit of ethical acceptability. That biotechnology has progressed to the point where the traditional meaning of the body is brought into question is critical. The case for arguing the body from a perspective that reads it as wholistic[2], meaningful, relational and continually in a state of flux has implications for the future of medicine and any attendant ethical support. It requires a radical departure from a dualist interpretation of the repairable body, to one that places the relief of suffering at the forefront of patient care. Patient narrative is considered helpful in foregrounding individual care and the need for co-operative decision-making. It strengthens a flexible approach to bioethics capable of adapting to future sophisticated developments in medicine; it ensures inclusivity and multi-vocality, and allows for the creation of ethical norms and values worthy of the complexity of our times.

Keywords: Bioethics, Principlism, Organ, Donation, Transplantation, Body, Embodiment, Wholistic, Meaningful, Relational, Narrative, Care.

[1] Beauchamp, T L., & Childress, J F., (2013) *Principles of Biomedical Ethics,* 7th edition, Oxford University Press, New York.

[2] Two orthographic representations exist in text: wholistic and holistic. Preference is given to wholistic as this reading represents the integrated nature of bodily existence put forward in the thesis.

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Introduction and Background

Until the hospital doctor can look down on his dying patient whose life as he knows he cannot save and sees in him the chance of life for the patients of his colleagues; until donor organs are recognized by all of us as the pieces of human tissue they are, waiting to be burned or buried a few days after death; and until opting out legislation has been introduced to this country, making available for transplantation all viable organs unless the deceased in his lifetime has recorded his dissent, this tragic waste of life will continue.[3]

The key aim of this study is to investigate and to provide a timely and practical alternative to the predominant bioethical model Principlism – a model that continues to be heavily criticised.[4] The model outlined in *Principles of Biomedical Ethics* now in its 7th edition, was written originally in the mid nineteen seventies by Beauchamp the philosopher and ethicist and Childress the philosopher and theologian.[5] Much of the criticism centres on the model's lack of provision for practical solutions to the dilemmas faced by medical professionals day-to-day. The four principles of autonomy, beneficence, non-maleficence and justice comprising the Principlist model remain firmly in place despite suggested alternatives and additions put forward by numerous eminent bioethicists.[6] Instead Beauchamp and Childress over the years have acceded to their critics by including criteria from ethical alternatives such as Virtue Ethics in an effort to bolster their original framework, to little avail. Considered both simplistic and out-dated, Principlism needs revisiting in its entirety in order to provide a bioethical model that will meet the needs of medical staff and patients, given the rapid pace at which technology is advancing and the inevitable influence that such developments will have on bioethics in general. In this study bioethics is read through Organ Donation and Transplantation. I believe such an area of specialist medicine will present a robust challenge to Principlism, since transplant medicine sits at the extreme limits of ethical decision-making. In this context. Lesley Sharp observes that:

> Organ transplantation presents an ideal context for studying scientific morality precisely because it has long stood as a gold standard in clinical work, ceaselessly blending technical sophistication with medical innovation. Economic, social and clinical stakes are extraordinarily high within this domain, legitimating especially bold undertakings….Organ replacement is regarded by many as requiring among the most complex and prestigious surgical skills; a hospital's stature may depend on the

[3] Sells, R A., (1990) Organ commerce: ethics and expediency, *Transplant Proceedings*: **22:931-932**
[4] See Chs.4 & 5
[5] Beauchamp, T L., & Childress, J F., (2013)
[6] See Ch.5

> number of transplant surgeries its staff perform annually; and pronounced shortages of life-saving organs underscore the critical state of transplant medicine.[7]

This research is especially influenced by experiences of healing and health improvement gained in my eleven years as a kinesiologist specialising in wholistic health. No matter how awe inspiring transplantation medicine is, it is surely the responsibility of the medical professionals in this domain to take account of sociological, legal, philosophical and spiritual perspectives and the wider effects involved when they are operating in and making life-changing decisions in such an intimate and sensitive setting. Certainly it is within this context that I believe a highly developed sense of what it means to be 'my body' is demanded.[8] The body as complex and multi-layered is a vital topic, and one that appears to have been largely overlooked in the process of the development of an appropriate bioethical framework for medical matters in general. And furthermore within an ethical framework that seems to override what it means for us all to live 'life in all its fullness' that is a life that encompasses physical, mental and spiritual health.[9]

It could be said that medical treatment of whatever kind needs to embody the 'life in all its fullness' principle, since it is germane to our overall state of health whether we are ill or not. But in the case of transplantation medicine it has particular significance in how organ donors and recipients are treated both pre- and post-operatively. Apart from blood donation in no other medical circumstance is a third person, either living or deceased, involved in the restoration of a certain level of health to someone in dire need, and in many cases, of a stranger's internal bodily input.[10] Granted that shortage of organs and numerous other resources within the National Health Service (NHS) are at a critical level, and time spent with patients is at a premium, I am not advocating that clinicians have little concern for those within their care, rather that the ethics which underpins such care is both limited and limiting for the patient as well as the medical staff.[11] It is critical that an approach which views humanity as wholistic, relational and meaningful, should focus on the wider needs of the patient; those needs which go beyond the physical, beyond the everyday, needs which

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[7] Sharp, L A., (2014) *The Transplant Imaginary: Mechanical Hearts, Animal Parts, and Moral thinking in Highly Experimental Science*, University of California Press, Berkeley, p7.

[8] 'my body' refers to the body of each and every individual.

[9] Spillman, I D., (2016) Faith-based health care in *The Lancet*: **387:10017:429**

[10] Although not the remit of this study, three parent families should be included here as medical technology advances with gene splicing and the implantation of donated normal genes to offset potential mitochondrial defects in the foetus.

[11] Frank, A W., (2004) *The Renewal of Generosity: Illness, Medicine and How to Live*, University of Chicago Press, Chicago, Ch.4.

reach into a narrative of their individual suffering and its consequences for the relief of ill health.

Confronted frequently by medical demands such as the extract at the start of this chapter by Professor Robert Sells, a consultant surgeon, in his paper from the 1990 Transplant Proceedings - we might be forgiven for asking why the human body, our body, is considered in such a dispassionate and detached manner in the event of death. His comment rather has both personal and ethical significance. That there is a global shortage of organs for transplant begs the question - should we donate an organ or organs during our lifetime or indeed after death to help alleviate the chronic suffering of those waiting patiently for the phone call that advises them that a suitable organ is available, and thereby the chance of a longer life?[12] The demand on us all is not to be underestimated. What is our purpose in this context? Is it that we couldn't bear to see a loved-one die, or is it maybe that we have been cajoled into a decision which would leave us feeling guilty if we chose not to donate? Donation is highly complex. It is not merely a matter of signing on the dotted line to a donation register. Or even agreement to go along with presumed consent. In the case of living donation the procedure involves vital cost to the donor, and in the case of deceased donation, to the relatives who might be faced with a very responsible decision on behalf of their loved one at an extremely emotional time. Fuelled by increasingly sophisticated medical and scientific knowledge, there can be no doubt that we are in an age of dynamic biotechnological progress especially in the area of highly technical and complicated surgery such as the transplant of organs, requiring considerable expertise by those concerned. The power of the clinicians to improve mechanically the quality and potential life expectancy of those who might otherwise remain chronically sick or indeed could die, has far-reaching consequences not only for medicine overall but for patients, and in this case for donors in particular. I firmly believe that the Western medical model has hitherto remained narrow in its focus within today's highly specialised and personal areas of medicine - areas that surely demand a fuller and more equitable interpretation of the human body than merely biological structure can begin to express.

A major issue beleaguering humanity, which I maintain causes all manner of illnesses, both physical and mental has resulted from being caught up in the never-ending web of materialism. Humanity has been seduced into believing that status, power and potential

[12] Even in 2017 with improving figures for donation the ratio of those who will die compared with those who will receive an organ remains persistently at 3:1. See National Health Service Blood and Transplant (NHSBT) Activity Report for 2016-2017.

comes from acquisition on diverse levels, be it from goods - cars, house ownership, positions at work, and equally importantly to many, from how we look.[13] The media, commercial markets and public institutions have nurtured this culture over centuries. In short we have embodied capitalist materialism and the results are proving to be at the cost of humanity in all its fullness. William Connolly the political theorist, in *Capitalism and Christianity, American Style* claims that the global dimension of capitalism entangles everyone with everything.[14] One of the central tenets of this study is that we need to shift the popular interpretation of materialism as the acquisition of goods towards a more profound understanding of the meaning of matter itself.

My research has covered a wide-ranging review of bioethical issues concerned with organ donation and transplantation enumerating an array of associated problems from the scarcity of suitable organs and discussions concerning the legal status of consent - both informed and presumed, to the examination of different models that have been proposed for establishing appropriate ethical practice in actual cases. In addressing what is considered to be the dominant model of Principlism, Beauchamp and Childress's *Principles of Biomedical Ethics* is cited since it is the text of choice for many medical schools globally. This model is believed by some ethicists to have proven of worth for practitioners and patients providing some kind of rule of thumb or starting point. Considerable space has been given however, to critiquing the ways in which existing interpretive and evaluative approaches within donor and transplant contexts are now failing to prioritise relationships of care, compassion and empathy between patients and medical practitioners as a means for promoting recovery, or engaging with suffering, pain and to some extent death in a deeply meaningful way. Existing practices fail to give the notion of human embodiment its due at a time when medical technologies are advancing in sophistication, but rather tend still to value the capacity to express rational and intellectual control over medical matters rather than recognising and responding to affective or embodied states.

Part of the problem lies in the patriarchal influence that over the centuries has been exercised within many institutionalised organisations of which medicine is a part. Duality

[13] Demographic data to establish social status. See UK Census 2011 under People, Population and Community, Office for National Statistics, www.ons.gov.uk/census/2011/census accessed on 26/05/2016. See also Bryden, I., 'Cut 'n' Slash': Remodelling the 'Freakish' Female Form, in Althaus-Reid, M., & Isherwood, L., (2008) (eds.) *Controversies in Body Theology*, SCM Press, London, p29.

[14] Connolly, W E., (2008) *Capitalism and Christianity American Style*, Duke University Press, Durham, North Carolina, Ch.1.

between mind and body, God and not God, male and female and so on are issues that have had considerable impact on humanity in general. James Nelson believes for instance that:

> We yearn for a new time when the dualism that has made spirit and bodies enemies of each other will be no more. We yearn for a time when the dualisms that have made men fear and control women, that have made heterosexuals fear and control lesbians and gay men will be no more. We long for the time when human sexuality, in spite of all its ambiguities, will be more integrated with our experience of the sacred and with the vision of God's shalom.[15]

Lisa Isherwood and Elizabeth Stuart argue that one of the dualisms perpetuated by patriarchy is the dualism of sacred/profane in which 'women's bodies have been placed on the profane side of the equation.'[16] Patriarchy profanes menstrual and post-partum blood, linking it with death, disorder and chaos. Thus the practice of patriarchy has been questioned by many a feminist theologian as it effectively excludes women, treating them as inferior, not only in the workplace but also in their everyday lives.[17] That women share this flaw of constant flux with all matter is problematic in patriarchal domination since it disrupts belief in the divine as a static, unchangeable God of law and order that is ultimately pure spirit. Yet quantum concepts have demonstrated that there is no dualism between spirit or energy and matter and matter itself is neither fixed nor predictable. The whole of the universe is in fact a complex web of interrelationality in a constant state of flux. Important points I shall be returning to in the chapters that follow.

The heart of this study therefore offers the wider perspective of approaching the body not only as wholistic, relational and meaningful, but equally dynamic and creative, in direct contrast to the static, dualist model based on the mind-body Cartesian interpretation prevalent in much current medical practice.[18] Alternative approaches to relieving pain and suffering base much of their praxis on esoteric anatomy. That is, certain Indian and Chinese ancient traditional mappings of the subtle energy pathways that interpenetrate each and every system in the body and expand and interconnect outwards to those energy pathways implicated in the universe and beyond. These mappings have formed the basis of such modes of wholistic healing as Ayurveda, Acupuncture, Kinesiology, Chiropractic and other systems of vibrational and energy medicine. The thesis governing each of these modalities

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[15] Nelson, J B., (1992) *Body Theology*, Westminster, John Knox Press, Louisville, Kentucky pp15-16.
[16] Isherwood, L., & Stuart, E., (1998) *Introductions in Feminist Theology 2*: *Introducing Body Theology*, Sheffield Academic Press, Sheffield, p80.
[17] Isherwood, L., & Stuart, E., (1998) p81. See also Bryden, I., at note 12.
[18] While considerable work is underway in bringing mental health into the main frame of clinical praxis, however, this development has yet to demonstrate any challenge to the standardised medical model as practised in the West.

rests on the belief that bodily health - physical, mental and spiritual - is maintained through the constant flow of energy through the body; when energy becomes stuck as a result of a traumatic event, the outcome manifests itself at the physical level as pain and illness, and at the subtle, invisible level as suffering. I am however not advocating alternative methods of healing as any kind of approach to transplantation *per se*, rather that there are other ways of perceiving human being which have some relevance to treating the body with the greater understanding necessary to the process of complex medical decision-making. I am using an alternate means of viewing the body thereby in order to assess the impact of treating it in any gender assignment as static and hence unchanging.

Whilst mainstream medical science frequently dismisses alternative approaches as 'quackery', the results of placebo effect, or just plain unscientific and therefore neither subject to rigorous testing nor repeatability, anecdotal evidence suggests otherwise. Numerous people have found long-lasting relief from seeking help through non-traditional medical methods, given the opportunity to express their illness through their own story to a practitioner who has both the time and the skills to listen.[19] Equally, anecdotal evidence would support the significance of treating the body as an energetic or vital force dynamically interrelated with the universe. Underpinned by twenty-first century quantum ideas of the building blocks of all that exists, the splitting of the atom into even smaller constituents for instance into electrons, protons, neutrons, quarks and so on, the notion that all matter can be interpreted as particles and waves of energy, lends further credibility to the view espoused by ancient Chinese concepts of the body which were proposed around 202 BCE to 220 CE.[20] Could it be as Catherine Keller suggests that: 'the actual individual - yourself or one of your innumerable electrons - takes place as an actualisation; there is not an enduring identity of matter or of you; there is materialisation in this moment. And the next moment. And the next. And at each moment we can say that you enfold prior moments, and the great manifold of events - electronic, molecular, genetic, social - making up your universe; and in that moment unfold it all otherwise.'[21]

The question remains however of whether any ethical model could be sufficiently dynamic to support not only current, well-established medical techniques but also the use of stem cells, gene editing and mitochondrial replacement involved in three-person parenting,

[19] Patient stories on practitioners' websites whilst I appreciate are equally marketing pitches, do offer important insights into the healing potential of alternative approaches. See Kinesiology Federation under News: Case Studies and Client Testimonials at www.kinesiologyfederation.co.uk accessed on 16/02/2016.
[20] Kaptchuk, E J., (1983) *Chinese Medicine: The Web that has no Weaver*, Rider, London, p24.
[21] Keller, C., (2015) *Cloud of the Impossible*, Columbia University Press, New York, pp142-3.

xenotransplantation, or even of digital technology such as artificial neural networks involved in robotics. Is it feasible to ask a robot to operate on a patient with 'respect for their body' for example?[22] For robotics is increasingly where medicine in general and surgery in particular is heading. Are we in fact moving into an era in which reflection on the nature of humanity becomes more and more pressing? Is it time to consider such concepts as post-humanity? Whilst many advances are still in their infancy, it is important that progressive techniques are built into any potential ethical approach. These will have increasingly meaningful impact on the future of how we wish the body to be *seen* including treatment either for restoration of a certain level of health or for the conduct of research. Not to speak of the inevitable changes that such progress will bring, including ways in which we might view the body years into the future.[23] Should any bioethical model reflect this dynamic representation of human being if it has any value in underpinning the medical decisions and surgical procedures involved in patient care? Can we separate out from ethical frameworks co-operative/integrated decision-making from actual surgical procedures where mistakes could prove costly on every level for medical professionals? As the blurring of boundaries between fleshy existence and biotechnology evolves, personal responsibility will become increasingly an area of concern. Whilst sworn by fewer doctors, there is after all the Hippocratic Oath in its multiple modern forms to underpin individually responsible medical praxis.[24]

The setting out of key ethical arguments in this study brings the reader into the picture through examination at depth of the issues involved in organ donation and transplantation. Which are themselves in a constant state of flux. And also through a critique of the several ethical models offered as alternatives to Principlism, to ascertain their appropriateness in solving the problems that have been raised by a number of clinicians. The typically Western medical construal of the body as mechanistic and standardised is shown to be limiting. That we are embodied beings I believe will no doubt shift the emphasis away from an entirely rational account of the ethical requirements underpinning organ donation and transplantation. It will further call into question the applicability of current ethical approaches to be helpful as guidance in responding to day-to-day medical dilemmas. One of the major complaints of the current most popular model is that it is not expansive enough

[22] Robotic surgery has been in use for more than a decade in multiple speciality areas such as cardiothoracic, colorectal procedures and some organ transplantations. See: www.nyulangone.org/ surgery-center accessed 19/06/15.
[23] See Rosi Braidotti's book *The Posthuman* (2013) Polity, Cambridge, and Coole & Frost (eds.) *New Materialisms* (2010) Duke University Press, Durham, New Carolina, for some interesting accounts of future perceptions of the body and their implications.
[24] www.pbs.org/wgbh/nova/body/hippocratic -oath-today.html accessed 10/10/14.

and is simply an exercise to be gone through. [25] The bioethicist and one-time editor of the *Journal of Biomedical Ethics* Raanan Gillon, appears to defend vehemently the four principles model however, by asserting that those who see Principlism as simplistic and a mere 'tick-in-the-box protocol' are misusing the system.[26] But evidence has shown this so-called 'tick-in-the-box' exercise to be the manner in which the model is used more often than not.

We might ask as a consequence, why bioethical issues have remained so persistently problematic when there has been a notable framework in place for around forty years to offer at least some help in meeting the day-to-day dilemmas that medical profession have to deal with in the course of pursuing their aims. Surely we should expect ethical input at the very least to offer reassurance that the appropriate courses of action in whatever circumstances are being undertaken and more importantly supported. In fact the plethora of textual resources discussed in this study have demonstrated the need to go over old ground in an attempt to reach some or even more appropriate and thus *improved* ethical resolutions, yet relatively little improvement or amendment to the much used model has been revealed, or equally to the arguments put forward. Noteworthy it seems that alternative models have fared little better. More focus on the patients and their everyday challenges with illness is unquestionably significant. The meaning of illness from the patient's perspective, will inevitably exercise huge influence on their daily lives and future plans, and some further investigation apart from their individual case history might effect considerable improvement in medical practice.

In turning to the application of bioethical models in general, despite the claims of Beauchamp and Childress to the universal applicability of their model, I don't believe any model will ever accomplish the goal of being universalisable. We are all individual. Thus any model claiming universability will at best be framed along utilitarian or deontological lines. In this vein Gillon himself in the same paper defending the four principles admits:

> [The] four principles approach does not necessarily lead to better medical practice… I have also agreed that it does not provide a universalisable method either for dealing with moral dilemmas or for dealing with fundamental disagreements about the proper scope of these principles - but nor are there currently any other such methods that are both universalisable and widely accepted.[27]

[25] See Rosamund Rhodes, Good and not so good medical ethics, and Wing May Kong, What is good medical ethics? A clinician's perspective, the *Journal of Medical Ethics* 2015, **41:1:71 and 79**
[26] Gillon, R., (2015) Defending the four principles approach as a good basis for good medical practice and therefore for good medical ethics in *Journal of Medical Ethics*: **41:111-115**
[27] Gillon, R., (2015) **41:111-115**

It is of concern that Gillon believes there are no other forthcoming models to replace Principlism, so who and what does the framework support? Paradoxically Gillon goes on to suggest: 'I have argued that none of these features undermines the acceptance of Principlism or the four principles approach - when properly understood - as affording a good and useful moral framework. It is a framework that is compatible with other universalisable philosophies including deontological, utilitarian and virtuist approaches, as well as several others.'[28] There appears to be an element of sitting on the fence here. There is also a hint that the four principles are neither comprehensive enough nor cohesive, but rather require one or more bolted-on theories to make any claim that could be remotely considered universally applicable in their terms.

It is not necessary to be an experienced and well-known bioethicist to notice that there is extreme customer discontent within the healthcare system.[29] There is enough current evidence to show questions of the perception of the body in the twenty-first century - questions of value, doctor-patient relationships, ownership and agency, and issues of care and concern in treatment protocols remain vital. In this vein, the Francis Report advised the need to make the patient and their care the centre of any medical enterprise.[30] Thus any ethical input has to follow suit since it is clear from the research cited that treating patients mechanistically is neither producing patient satisfaction nor is it solving the problem of care either at the time, nor indeed in pre- or post-hospitalisation. A deeper appreciation of alternative themes of the body and the nature of biotechnical progress in the twenty-first century as they individually and collectively impact on medical treatment and sensitive decision-making processes is both timely and paramount.

An overview of the chapters

Chapter 1 – The Approach – An Incarnational Perspective offers reasons why we need to focus on the body and arguments for avoiding Cartesian dualisms. To accomplish such change, a variety of methods have been included that contribute to the overall thesis: medical, theological and philosophical theories, bioethical concepts, empirical findings, and reported experiences of patients and medical staff in general and transplantation medicine in particular. The inclusion of such a large range of materials means that a traditional

[28] Gillon, R., (2015) **41:111-115**
[29] See Ch.4 p89 to this study.
[30] Mid Staffordshire NHS Foundation Trust, (2013) Public Enquiry, Executive Summary, HMSO, London, www.gov.uk/publications/ otherwise known as the Francis Report.

methodological framework to guide the arguments in the research is not useful. It is critical to place the diverse nature of bioethics into an appropriate context to appreciate the range of interrelated concepts that fall within its remit. Such diversity underpins the rationale for using the term 'approach' rather than method. Furthermore in order to position organ donation and transplantation within its own highly complex context, desk research based on informatics involving historical as well as current data was considered a sound basis from which to argue an alternative approach. The discussion turns to incarnation theory albeit in secular form as the most relevant and indeed the most useful approach to argue against Principlism. Incarnational theory resonates readily with alternative interpretations of the fluidity of humanity and beingness/becoming - and chimes with the philosophy that all matter as energy can be seen through the modern application of quantum physics principles. It also harkens back to ancient traditional views of the body that have been shown to have long lasting influence in complementary medical praxis. Theories about humanity are thus presented in the study as complex and multi-layered, rather than reductionist and mechanistic.

Chapter 2 maintains that it is inconceivable to be dealing with the body in any related context devoid of a deeply considered discussion of what the 'body' actually means. Views from ancient Chinese and Indian maps of the body as energy are presented with pertinent summaries of the meaning and philosophical exegesis behind them. The discussion moves on to linking and substantiating the mappings with a theoretical discussion of twenty-first century quantum physics in order to set out and argue the thesis that alternative approaches to medicine have a valid input into the meaning of bodily becoming. The links between the body as a structure, as energy, as quantum concepts of particle and wave are established. Implied in this viewpoint is the suggestion that the body is inextricably connected at a profound level with all that exists. As Lisa Blackman argues, the body is not a bounded entity but rather multiple, extending and connecting to other bodies human and non-human which produce different kinds of body and different ways of enacting what it means to be human, and shifts the emphasis to what bodies can become.[31] And Ervin Laszlo contends the living organism cannot be reduced to the interaction of its parts without losing its 'emergent properties' - the very characteristics that make it living.[32] Such scholarly wisdom serves as a metaphor for the faith, hope, trust and love which underlies the body's own power and capacity for healing both sickness and suffering.

[31] Blackman, L., (2008), *The Body: Key Concepts,* Berg, New York, pp1-3.
[32] Laszlo, E., (2006) *The Chaos Point*: *The World at the Crossroads*, Piatkus Books, London, p92.

Chapter 3 is critical in highlighting current issues in organ donation and transplantation that place this specialist area of medicine into its appropriate context. It has especial significance in emphasising the fundamental support factors involved in any ethical decision-making, but more importantly acts as a contrast and grounding for arguing a focus on the body as narrative for other chapters. In greater detail Chapter 3 calls attention to the growing concern for the lack of resources available for organ transplantation and the means by which health, legal, and ethical institutions underpin the whole donation and transplantation process. It sets out current statistics including living and deceased donation, legal regulations for donation both within the UK and globally, and methods of consent for both donor and recipient. And in this vein opens out the thorny issue of presumed consent in order to prepare the ground for more profound discussion in Chapter 4.[33]

A critical analysis of those sources informing past as well as current ethical debates on the subject of transplantation medicine is presented in **Chapter 4**. The intention is to highlight both the strengths and weaknesses of those debates in order to add weight to a proposed alternative approach to the main ethical framework that currently operates in the UK. Organ donation and transplantation are both complex and complicated events, involving major surgical intervention into the body. Together they remain ethically challenging issues for those effecting and those who are affected by the processes. The getting of presumed as well as informed consent remain high on the bioethical agenda since individually they reach into the very nature of human being and perceptions of the value of the body. Payment of any sort for organs and the insistence on altruistic organ donation are particularly problematic since the whole notion of altruism is difficult to ascertain. The question revolves around whether we can gift anything purely for the sake of it, with no ulterior motive, when it may be reconciled within ourselves as a charitable act, particularly where relatives of the donor are concerned. The issue remains that payment for organs is illegal in the UK, no money must change hands throughout the entire process. There is a strong argument that payment for organs is considered to pave the way for the sale of organs in an open market with all that entails. Organ trafficking however persists globally and those who are paid to donate are often the least able to benefit from medical assistance post surgery. Ethical unease continues unabated in the matter of organ acquisition and transfer with the result

[33] For information and to give a snapshot, a timeline in the specialised medical domain of donation and transplantation has been included in an appendix at the end of the study to show the progress of organ transplantation techniques and the management both legal and organisational in the UK.

that organ shortage is directly blamed in many instances on the lack of progress in solving such ethical impasses.

Chapter 5 discusses both the dominant bioethical model - generally understood as Principlism, and further ethical models suggested by eminent bioethicists as replacements or additions to that proposed by Beauchamp and Childress. Discussion considers a variety of ethical models, both current and historical, in order to lend force to my contention that most frameworks fail to live up to their original intention, which is to offer guidance on medical decision-making in order to provide benefit and a restoration of an improved level of health to the patient. The progress of modern medicine continues to be rocky suffering from diverse shifts in the political arena including ways in which healthcare is dispensed. Such shifts have impacted on the development of bioethics over the years and may account for the resistant manner in which the dominant ethical model remains in its original form and is still in use. The four principles of autonomy, beneficence, non-maleficence and justice comprising the framework are critically analysed in the chapter for their effectiveness in providing the support that medical professionals seek to underpin their decision-making. They each have significant drawbacks, although the concept of autonomy has made a major contribution towards the establishment of informed consent. More problematic however is Beauchamp and Childress's claim to a common morality that is universal in its application, such a claim appears paradoxical. Bioethical models based on utilitarian principles eschew the individual in favour of the greatest good for the greatest number, and thus sit as a meta-ethic far removed from day-to-day moral concerns. Alternative approaches to Principlism discussed in the final section of the chapter reveal similar difficulties of being too generalist to overcome the problems associated with placing the patient at the forefront of medical decision-making. However, greater space is allotted to the ethics of care model. It has the potential to link more readily with a more fluid interpretation of the body rendered possible by adopting a narrative approach to overcoming the difficulties associated with the static model devised by Beauchamp and Childress.

The discussion in **Chapter 6** centres on story beyond the patient's medical history, and though medical history is vital in assessing treatment protocols, I consider that the patient's own story has significant relevance for their future wellbeing and healing. Clarification of the difference between pain and suffering and the subject of the fear of dying is an important starting point since these sit under the surface of many a story within a medical context. The conflation of pain and suffering is unhelpful. The superficiality of pain and the depth of

suffering - which is considered to be deeply embedded in the subtle energy system, render pain to be treatable and suffering frequently to be ignored. Narrative[34] I believe, offers a gateway into patient suffering and thereby a prompt to begin the process of healing often before any treatment takes place. Given that care requires paying close attention to the needs of the other, and in the case of transplantation to those involved in the process, the rationale for choosing narrative as an appropriate alternative to the traditional bioethical framework of Principlism is the focus of the discussion in this chapter. A positive healing prognosis I believe rests on continued care throughout the process of pre- and post-surgery. The narrative input of both the donor and the recipient is fundamental to caring and thereby becomes instrumental in garnering support during times when either physically or emotionally their anxieties may be relieved. Their experiences after all are unique in the intervention they are about to undergo. Story puts both the patient (as both donor and recipient) and the doctor mutually at the forefront of inclusive decision-making in prolonging life or in circumstances where that is certain not to be the case. In both situations however hope is established so that life can carry on however limited, by the medical practitioner committing and responding to the needs of the patient.

A more fluid interpretation of what is 'good' for individuals and for those who are ill in particular is vital. Viewing the body as multiple and porous, as ever becoming through the process of individuation, contributes effectively towards accomplishing the aim of grounding the seemingly intractable complexities of technical advancement especially within transplantation medicine. It renders with greater clarity the effect on patients, donors, family and medical professionals. The focus for **Chapter 7** in establishing a rationale for narrative through the processes of multi-vocality and dialogue, offers greater insight into development of any ethical approach. People tell stories not just to work out their own changing identities, but also to guide others who will follow them. Ill people while still surrendering their bodies to medicine, increasingly try to hold onto their own stories through the process of gathering those around them who they can trust to support them as the people they are, unencumbered by the role they have assumed as a patient living through and experiencing illness. The necessity of dialogue in maintaining identity through illness therefore cannot be underestimated. When dialogue breaks down for any reason, the patient becomes finalised - cut-off from who they are with the result that their healing is curtailed, because they cease to exist. For a plethora of reasons, time being one, doctors regularly finalise patients so that the patient is silenced and in effect so too is their healing.

[34] See Ch.6 for a fuller explanation of narrative.

Chapter 8 points towards potential future developments in biotechnology and the kinds of influence such progress will exert on bodily becoming. There is an urgent need to develop criteria to underpin bioethics since these will have impact on future legal rulings - which as the Timeline shows lag far behind progress in the field. Moreover this chapter returns to a focus on the body as pivotal to the thesis in this study and the issues that were raised in the Introduction. It brings into sharp relief the real need to progress beyond the frameworks currently in use. Moving rapidly towards the merging of our ways of life with science and technology inevitably requires a different perspective on human being. The discussion in this chapter therefore considers the idea of the posthuman as a metaphor for the development of any ethical input concerning the body, the nature of understanding *being* in general and within medicine in particular. Such contemplation, albeit speculative is critical. Arguments discussed concentrate on the central issue of how the process of the fusion of technology with the body and its functioning will impact on future bioethical approaches, given the blurring of the boundary between science and a fluid interpretation of the individual. The chapter covers contemporary ideas on living matter, ethical problems that might be associated with future of biotechnology and posthumanity in relation to care.

There is a good deal of scepticism surrounding biotechnical progress.[35] The blurring of parts of the body with other persons, technical devices and non-human organisms renders humanity hybridised. Devising new social, ethical and discursive schemes of subject formation will become increasingly pressing. Posthumanity is the opportunity to deconstruct and recast the traditionally held anthropocentric form, function and meaning of the body in diverse ways. It will be challenging because significant normative questions will no doubt ensue. The question for bodily becoming is not whether such change is acceptable - although this is an important issue, it is rather more critically a case of how we *manage* the use of any technology that will impact on the health and well-being of the body in the twenty-first century and beyond. What will an ethical approach to care look like given the immense concentration of effort in creating technical artefacts of such sophistication and complexity? It seems clear that the ideal of perfection, precision and efficiency remains foremost in every imaginary field overriding the needs of care and concern for the individual.

[35] The development and use of robotics in diverse environments traditionally served by a large often highly skilled workforce being the most significant at the time of writing this thesis. See progress in surgery and defence for example, portrayed in various journalist media.

Chapter 1

The Approach – An Incarnational Perspective

Now, more than ever…our place in the universe and the place of the universe in us, is proving to be one of active relationship. That is more than a scientist's credo. The separateness of our lives is a sham. Physics, mathematics, music, painting, my politics, my love for you, my work, the star-dust of my body, the spirit that impels it, clocks diurnal, time perpetual, the roll, rough, tender, swamping, liberating, breathing, moving, thinking nature, human nature and the cosmos are patterned together.[36]

Jeanette Winterson

Introduction

A fluid interpretation of human being defies a step-by step, logical following of a set of processes/criteria that reach conclusive results.[37] Bioethics being considered a 'soft' and messy problem area grounds the idea that *approach* would be a more fitting term to pursue in this study. Trying to fit any static, bioethical model representative of the dynamic nature of human being into a traditional methodology is naturally problematic.

This chapter focuses on the body and its meaning. It will introduce the body as wholistic; the body as relational; the doctor-patient encounter; and bodily experience in illness including the implication of Cartesian dualist interpretations of the mind body split which has so long engendered the separation of the body from itself, and ultimately from all that is or continues to become in the cosmos. As stated in the Introduction and Background, an

[36] Winterson, J., (1997) *Gut Symmetries,* Vintage, New York, p84.

[37] Although quantitative elements were critical to position the underlying problems of organ donation and transplantation in terms of numbers and types of donated organs, gender and ages of recipients for instance, these criteria are not strictly within the sphere of my research. They were however useful indications of the scale of the issues.

incarnational approach is reasoned as more appropriate to embody human being/becoming and therefore is the thread connecting each part of the study.

In order to present an inclusive picture of both the problems of organ donation and those of transplantation, a crystallisation of medical and philosophical theories is presented including bioethical concepts, empirical findings, reported experiences of transplantation and ad hoc conversations with alternative therapists. While the study is an eclectic mix - a *smörgasbørd* if you will of research into an ever developing biotechnology, '**what do we mean by "body"?'** is the overriding theme on which the whole study is based. The body is not merely a matter of structural and objective explication but encompasses a multiplicity of concepts that inevitably demand an approach capable of accounting for such complexity. I argue therefore that without some understanding of what 'body' connotes a deeper appreciation of the value of humanity will not be afforded and thus the help to patients - who after all *are* bodies in dire need of appropriate and significant medical assistance - will not be forthcoming.

The problem of any medical intervention is necessarily concerned with people: the clinician, the patient and in all cases those who have contact with both including relatives and close friends, and being 'messy', concrete solutions are rare.[38] Ethics equally is a slippery subject, a veritable minefield - there are no hard and fast rules and even within the law numerous exceptions and controversial decisions exist. The key question is why organ donation and transplantation is privileged here as an example above any other medical issue? As previously discussed in the Introduction no other surgical procedure necessitates the input of a third party either deceased or living - a point that has profound implications for any ethical process.

The Body

Bodily experience is foundational to our moral agency: our capacities for action and power, our abilities to tolerate ambiguity, our capacities for moral feeling. The body has ethical and societal relevance in a host of ways. Our bodily experience significantly colours our interpretations of social relations, communities and institutions that are the stuff of ethics and our words are vehicles by which we express ourselves in interrelationship with humanity

[38] Contrast 'soft' problem such as solve the issues of Syria, with a 'hard' problem where solving a mathematical problem such as adding up a column of numbers would have a solution. See Checkland, P., & Scholes, J., (1990) *Soft Systems Methodology in Action*, John Wiley, Chichester.

and the world. Richard Niebuhr points out that meanings and values arise out of the interaction of our bodily reality and our interpretive capacities as social relational beings.[39] Those meanings that contribute to our wholeness as body selves in relation are therefore what we deem authentically valuable and thus ethically important.

Although the lived body in everyday life is not the explicit focus of our attention, we do have some conscious notion of it, it is *me*. Maurice Merleau-Ponty argues that the role of my body is as both perceiver and perceived, there is no duality.[40] Under normal circumstances therefore, I do not perceive my body purely as an instrument. In contrast Jean-Paul Sartre illustrates his view of the body instrumentally, in an account of the act of writing, but he too sees the body as non-separate:

> I am not in relation to my hand in the same utilizing attitude as I am in relation to the pen; I am my hand …I can apprehend it - at least in so far as it is acting - only as the perpetual, evanescent reference of the whole series …my hand has vanished; it is lost in the complex system of instrumentality in order that the system may exist. It is simply the meaning and orientation of the system… We do not use the instrument for we *are* it.[41]

Whilst our everyday experiences are often taken for granted and our bodies are always with us we do have a sense of identity, of the characteristics that comprise our make-up. Personal identity encompasses what we are: this specific biological organism, with a history and memories, thoughts and particular character traits, all of which change over time. Yet they are anchored in sameness because of the temporal connections existing between present, past and future. My body is not just one body among others, it is unique to me, it is *who I am* as a direct result of the possibility of my experience.[42] A person's body constitutes their selfhood, not simply because it is some thing they possess or own. Additionally we must not assume that our bodily condition is static, it is constantly changing - we go through stages of infancy, puberty and adulthood and we age. These changes have the potential to modify who and what we are, our interrelationships with each other and the wider world. Consequently such changes raise significant normative questions.

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[39] Niebuhr, H R., (1960) *Radical Monotheism and Western Culture*, Harper & Brothers, New York, p102ff.
[40] Merleau-Ponty, M., (1962) *Phenomenology of Perception*, Smith, C., (trans), Routledge & Kegan Paul, London, **VI:** pp136-137.
[41] Sartre, J P., (1956) *Being and Nothingness: A Phenomenological Essay on Ontology*, H E Barnes (trans), Pocket Books, New York, pp426-427.
[42] Mackenzie, C., (2001) On Bodily Autonomy, in *Handbook of Phenomenology and Medicine,* Toombs, Kay S., (ed.) (2001) Kluwer Academic Publishers, Dordrecht, The Netherlands, pp422-423.

When illness strikes, the change is all too evident. Drew Leder proposes when we are in pain, that pain is 'ultimately a manner of being-in-the world.'[43] Pain reorganises our lived space and time, our relations with others and with ourselves and its importance is only revealed when set within this broader context. Pain disrupts life. The body accordingly emerges as 'an alien presence that makes a telic demand' upon us.[44] Pain frequently persists independent of its environmental cause and the new world which pain thrusts us into has a limiting effect. We are no longer out there in the world but stuck in the world of pain. According to Elaine Scarry moreover, intense pain is 'experienced spatially as either a contraction of the universe down to the immediate vicinity of the body or as the body swelling to fill the entire universe.'[45] In pain we are ceaselessly reminded of the here and now. Yet pain bizarrely effects certain alienation. Doctors report that patients frequently describe their pain as 'it' separated from 'I' or 'my' for instance.[46]

In the case of chronic problems as in disease, the contrast with acute medical issues is significant. Dependency on drugs, regular visits to hospital and frequent protracted periods of hospitalisation and recovery render the patient removed from the meaningful context of job, home, family and friends - in other words from *their* world. Even close family cannot share or fully understand the experience the patient is going through. Space and time constrict the patient's world to the world of the hospital. The everyday world in which the patient had recently inhabited now appears inaccessibly remote. As Leder suggests 'A landscape is viewed not as a field of possibility but of difficulties to negotiate.'[47] Disease, even more than pain is typified by complex patterns of dysfunction. In disease we are actively dis-abled. The onset of dis-ease brings into sharp focus personal vulnerability. Abilities that were previously in our control and belong to the habitual body have been lost and the loss of control intrinsic to that experience is accompanied by an acute awareness rendering the familiar world unpredictable. The patient's view on the world has dramatically changed - it is discontinuous. Kay Toombs argues that patients find prior assumptions about what is every-day and familiar to be 'strangely inadequate for interpreting the existential crisis.'[48]

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[43] Leder, D., (1990) *The Absent Body*, University of Chicago Press, Chicago, p73.
[44] Leder, D., (1990) p77
[45] Scarry, E., (1985) *The Body in Pain*, Oxford University Press, Oxford, p4.
[46] White J C., & Sweet, W H., (1955) *Pain: Its Mechanisms and Neurosurgical Control*, Charles C Thomas, Springfield, p108.
[47] Leder, D., (1990) p81
[48] Toombs, S K., (1992) *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*, Kluwer Academic Publishers, Dordrecht, The Netherlands, p20.

Nonetheless we do tend to engage with our pain and the body becomes an object to dig around even when this causes more discomfort. We surf the Internet, consult books on the body seeking for some kind of diagnosis or even ask friends or family for their opinion. We reflect on the past looking for possible origins of the current problem. When finally we consult a clinician we come to see our body 'in a series of technologically and conceptually extended ways that would otherwise be unavailable to us.'[49] My body becomes the object not just of perception and interpretation but of action and instead of simply acting from it, I act towards it. I become the patient and lose sight of *me*. Being a patient becomes a self-fulfilling prophecy. Consultation with the doctor often is a meeting between strangers, in spite of its intimate nature. It is in addition a meeting that is radically asymmetrical in the sense that the patient is the weak, help-seeking party asking for aid from the expert in health matters.[50] It thus demands some shared understanding. In the case of serious illness imparting such information risks superficiality marked by distinct difficulty in simplifying the highly specialised language involved, to create the necessary space for any level of mutual agreement and thence truly informed consent. This asymmetrical encounter Toombs believes, results from a distinct lack of a shared set of 'typifications.'[51] In the first instance the lived experience of illness is a situation in which the doctor categorises the patient's illness as a typified instance of a particular disease state, whereas the patient encounters their disorder as a unique personal event. In living through illness, therefore the patient does not experience bodily disorder as simply a specific kind of disease but rather as the unique manner in which disease has control over their particular life situation. 'To grasp something as a typification is to consider it apart from its ongoing constitution in lived time.'[52] Patients encounter illness in its 'qualitative immediacy.' Consequently in the experience of illness the taken-for-granted quality of daily life is called into question. The integrity of the self is primarily threatened and this fundamental loss of wholeness cannot 'readily be interpreted in terms of naïve typifications.'[53]

Asymmetry in the doctor-patient encounter has wide-ranging implications. Choices for treatment, as Fredrik Svenaeus points out, reduce very much to whether to accept a specific procedure or not, rather than a meeting of 'minds' which will come to some agreement

[49] Leder, D., (1990) p78
[50] Svenaeus, F., (2001) *The Hermeneutics of Medicine and The Phenomenology of Health: Steps towards a Philosophy of Medical Practice,* Kluwer Academic Publishers, Dordrecht, The Netherlands, p147.
[51] Typifications according to Toombs are shared understanding of the characteristics or attributes typifying a person. Toombs an Associate Professor of Philosophy Emeritus in the Centre for Advanced Research in Phenomenology in Texas, USA suffers from multiple sclerosis.
[52] Toombs, S K., (1992) pp 19-21
[53] Toombs, S K., (1992) p21

about the best path of action.[54] It demands a mutual trust and respect that renders the meeting an intense form of attunement. It places demands on the clinician to understand the body as far more than an object for study and technical manipulation to a richer, more rounded perspective that should include ways in which illness affects the daily lives of the patient. However, scientific typifications are characteristic of what Alfred Schutz and Thomas Luckmann call '[an] autonomous province of knowledge' a knowledge which is only readily available to experts.[55] Although it must be remembered that the clinician *is* able to interpret the illness of the patient in terms of their specific area of knowledge as both a specialised and scientific typification, and may wish to proceed with due haste ignoring the point that the patient does not conceive of their illness in the same manner.

There is a direct correlation between the experiencer that is the patient, and what they experience. This provides the grounds for the necessity of taking into account the manner in which each patient constitutes the meaning of their personal experience of illness and the way this influences their view of the world. No two patients will ascribe exactly the same meaning to their illness. As a result it becomes paramount to account for their individual world-view not only from their unique biographical perspective but also from the wider social context that is a feature of their historical and cultural backgrounds. As Andrew Elder and Oliver Samuel suggest, the clinician's lived experience is significantly different from the patient's.[56] Hence the doctor who can lay aside any preconceived notions about the patient's illness is better able to recognise and set aside prejudgments which may get in the way of exploring the meanings inherent in the patient's world. Mary Midgley captures the essence of the problem beautifully:

> Microscopes, those splendid tools of modern scientific method are also its most significant symbol. Microscopes reveal new patterns, patterns which can sometimes be of the utmost importance. But they make the original macroscopic phenomena invisible. When we want the facts at that everyday level, we have to put away our microscopes. If (for instance) the problem is why certain people are anaemic, we must answer questions about their way of living as well as ones about the constitution of their blood. For many of the most relevant of those questions, neither the microscope nor the scientific method that it serves is any use at all. (For instance: are these people happy? Are they fairly treated? How are they trying to live?) Different patterns different ways of thinking must be brought in.[57]

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[54] Svanaeus, F., (2001) p147

[55] Schutz, A., & Luckmann, T., (1973) *The Structures of the Life World*, Zaner, R M., & Englehardt, H T. Jr., (trans.), Northwestern University Press, Illinois, pp314-315.

[56] Elder, A., & Samuel, O., (1987) (eds.), *While I'm here, doctor*: *A study of change in the doctor-patient relationship*, Tavistock Publications, New York.

[57] Midgley, M., (1994) *The Ethical Primate: Humans, freedom and morality*, Routledge, London, p49.

Biotechnological progress provides us with unprecedented capacity for change. Thus in developing any ethical response to such progress we cannot simply assume that it is either beneficial or detrimental to humanity. Any normative question must always ask whether there are good reasons for accepting the consequent changes to human embodiment, in other words to who and what we are, and to what may follow as a result.

Reasoning an incarnational approach

The main focus of this study is *theoretica*l requiring an approach that considers in depth wholistic and relational concepts of the 'fleshy' experience of life,[58] and more especially to a life riven by illness both acute and chronic. I deemed qualitative research approaches to be more appropriate, to articulate and interpret meaning in humanity in general and life as a patient in particular. Whilst inductive methods are useful for capturing insights and richness of data, the subjective nature of inductive research renders results open to criticism for their lack of repeatability and thus confirmation or refutation of hypotheses. For this research however, the lack of repeatability is imperative since as a practising kinesiologist I found that no two patient experiences were the same and I found it to be the patients' story and individual experience which became the foundation for recovery. Such experience lends support for the argument that care seen through the lens of narrative and dialogue could be a useful ethical approach.

However, the search for a suitable qualitative method to progress the study occasionally led me down the odd blind alley since the corpus of textual information and evidence covering the field of transplantation medicine is vast and very loosely linked, thus rendering a particular avenue of thought difficult to pursue. In the end I chose to consider areas that might offer robust foundations for analysing and supporting my propositions.

Phenomenology

I turned to the phenomenological approach to illness as a possible avenue worth pursuing. Since phenomenology is essentially reflective upon experience focusing on the taken-for-granted assumptions of everyday life, it at first sight appeared to have some relevance. Such reflection involves the disengagement, or distancing from our immediate and on-going

[58] Nelson, J B., (1992) *Body Theology,* Westminster John Knox Press, Louisville, Kentucky, p42.

experience of day-to-day life in order to make explicit the nature of such experience and the intentional structures that determine the meaning of that experience. In Edmund Husserl's terms 'bracketing out'.[59] In medicine phenomenology explores the view of the body as experienced in comparison with the body as the object of enquiry. In illness it is powerful in examining doctor-patient relationships for instance or the gap between the patients' understanding of illness and the understanding of the doctor. The argument would follow therefore that the phenomena of illness as it is lived is markedly distinct from the scientific identity of the disease state, both of which have important implications for doctor-patient communication, negotiation and a shared view of the body and its present problems.
A phenomenological approach seemed very valuable save for the view that embodiment requires that medical professionals seek to:

> …promote capacities for dealing creatively with situations beyond personal immediate control, to experience pain and struggle as meaningful aspects of existence, to find hope in a commitment to shape the life one has been given within restraints so that it is expressive and personally significant, and to experience wonder, appreciation and joy for whatever level of activity one can carry out with altered capacities, [these] are emotional tasks that healthcare professionals must address in promoting authentic healing.[60]

'Authentic healing' starts with both the professional *and* the patient acknowledging their commonality as persons, who share suffering along with the rest of humanity which is more than mere emotions can express. What is required is a meeting that takes into account the wider issues and perspectives of each of the participants - the medical professional as well as the patient. It is one thing to recognise there is something amiss in medical praxis but yet another to 'promote capacities' to deal with the lacuna. A significant part of the answer comes from the patient herself rather than any medical professional 'promoting authentic healing.' Thus bracketing out, so much a feature of the phenomenological method turns out to be inappropriate when the goal is not so much to analyse the experience in its fullness as to come to terms with it from both the perspective of the patient *and* the medical professionals involved.

In contrast, the salient feature of this study is a reconsideration of medical professionals' approaches to caring and compassion through an engagement at some deeper level with *what it means for the patient to be ill*, to empathise by being alive to their suffering and not just their pain for, as I have implied, healing starts at the point of suffering, not merely with

[59] Husserl, E., (1931) *Ideas: General Introduction to Pure Phenomenology*, Collier Books, New York, p100.
[60] Mazis, G A., (2001) Emotion and Embodiment in Toombs, S K, (ed.), *Handbook of Phenomenology and Medicine*, Kluwer Academic Publisher, The Netherlands, pp197-214.

analgesics or surgical intervention. Through the process of a deeper engagement with the patient rather than the case history, the medical professionals are offered an opportunity to see things differently to open out their views and effect a change within themselves rather than merely the patient. It is a call to look outwards to the wider picture. As Rupert Sheldrake believes: all bodies, cosmic, animal and human have an effect upon one another and that effect can reach across space and time.[61]

Ethnography

Originally I wanted to 'get my hands dirty' and not view the topic at a distance. My aim has always been to offer a practical outcome, but one that reflects a deep understanding of the issues at hand. So whilst phenomenology gave me some useful ideas, it failed to offer insights toward a potential outcome that I feel should be by its very nature pragmatic. Ethnography became a possibility. It would have offered that very opportunity for me to 'get stuck in' since in-depth interviewing and analysis requires just the active engagement I sought. However, the point of this study is to take a fresher look at the problem and not get caught up with issues already well documented in academic texts and the media. And, moreover, those firmly held by clinicians themselves, whose ideology seems so deeply entrenched in a dualist interpretation of the body.

More meaningful deliberation and research I felt was required before coming up with a schedule of questions that would have offered sufficient 'fruit' to provide the practical alternative to that which is already in place. Since ethnographic research is a lengthy process ultimately the 'right' questions were not forthcoming sufficiently to elicit the kinds of response that would offer the creative outcome I was seeking. I believe this would have been almost certainly through an immature appreciation of the subject matter. Indeed many potentially ethical issues are still forthcoming even as I am in the process of writing-up.[62] Ethnographers might disagree claiming that participant observation would offer just the opportunity to tease out the real issues, but I was not willing to take the risk of getting embroiled in myriad well-known debates supporting standard medical approach and praxis. However I do not rule-out ethnography altogether since it could play a significant role in substantiating the findings of my research in any future study within bioethics generally.

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[61] Sheldrake, R., (1981) *A New Science of Life: The Hypothesis of Formative Causation*, J P Tatcher, Los Angeles, p13.

[62] Experiments in cryogenics are being funded by the US to enable the freezing of solid organs for periods of time including methods to defrost them, in order to increase the level of available organs, particularly hearts that are scarce, for transplantation. www.scientificamerican/article/u-s/

Finally on reading further about the body, body theology and the ethics of caring struck a chord, since they touch on wholistic, embodied awareness, and through continued research I became convinced that this would be the way forward for the rest of the study.

Incarnation and the body

Whilst this study is not theological in content, I have drawn on aspects of body theology as a helpful basis from which to argue that bodily becoming is a constant process, ever moving forward and linked to all that exists including divine existence which resonates with belief, faith, hope and above all love as essential human attributes. Such an approach also chimes with the fluidity of all life as evidenced by the concepts and philosophies of quantum physics, which have gained much credibility in recent years. The task of body theology focused on incarnation therefore is critical reflection on our bodily experience as the fundamental realm of connection to the divine, an experience that I believe to be significant. According to James Nelson the Christian ethicist, incarnation doesn't begin with doctrinal propositions, rather it starts with the 'fleshy' experience of life – 'with our desires, our bodily aliveness and deadness, with the warm touch of a friend.'[63] It is not however, a theological description of bodily life from a 'supra-bodily vantage point.'[64] We do not have bodies we *are* bodies. Incarnation therefore necessarily begins with our bodily/fleshy experience, even while it recognises that our experiences are filtered through interpretation of the apparent reality that we attach to our bodily life. The more connected we are with bodily reality, the more we are able to accept the world we experience. By contrast, the more distant from the body we are, the more separated we are from all that contributes to our awareness of our world, the greater the tendency to see the world as dualities, with either-ors, we or they, sick or well.

Isherwood and Stuart believe that dwelling spiritually within the physical body entails removing oneself as far as possible from the reality of that body, and so the issue with dualism rests in the notion that all that is truly worthy lies beyond the body and ultimately in heaven.[65] Routinely we have been taught not only is the body different from the real core of selfhood, it is also lower and must be controlled by that which is higher. Our language therefore continues to be strongly dualistic. The body appears radically different from *me*. *I have a body* seems much more natural than *I am a body*, or even *I am body*. Certain

[63] Nelson, J B., (1992) p42
[64] Nelson, J B., (1992) p43
[65] Isherwood, L., & Stuart, E., (1998) p16

experiences such as illness, aging and death seem to confirm the estrangement of the body. The body becomes an *it*, a burden, a thing to be borne, to be put up with, to be tolerated. In illness the body feels alien to us, it isn't unusual to hear someone say 'I'm not feeling myself today.' There is a disconnection and yet ironically we feel most fully ourselves when bodily connected with each other and the earth.

Thus incarnational theory offers insights into the very nature of humanity, its embodiedness and its value, an understanding that looks both inward and outward to the interrelationship of the individual to others and to the wider world. Caring is founded for instance in the sense of worth that I experience in the other. It requires a sense of participation in the other. It requires trust in the other. In proposing that human life is fundamentally valuable not merely because human beings place value on it, a body theological approach centres on the idea of faith. And whilst all judgements of value are based on faith - because we actually don't know, if to become more fully human means to live with greater self-awareness, greater capacity for faith, hope and love, then according to James Nelson and Jo Anne Rohricht any specific biomedical decisions should be made in ways that nourish, enhance and enlarge these inherent human qualities.[66]

By understanding humanity as embodied there is a shift from the traditional clinical approach to the body as a form of machine, to the ways in which consciousness affects the embodied self, and equally to the way in which embodiment influences and delineates consciousness. The body therefore can be seen as the articulation and actualisation of the self. Such understanding is not with the body object as studied by the anatomist or physiologist, but rather the body subject, the embodiment of our consciousness, our bodily sense of how we are in the world. It concerns the interaction of the 'givenness' of our fleshy realities and the ways in which we interpret them. It grounds an understanding of our bodily sense of connections to the world, our bodily sense of the space and time we are in and our bodily knowing of the meanings of our relationships.[67] It involves reintegrating the body, seeing the body as the embodiment of consciousness, with our interactions with reality and the ways in which we interpret them: 're-integration of the body wholistically is not simply an abstract hope, a revelation from outside imposed on a very different reality.'[68] Pierre Teilhard de Chardin once commented that we have been taught to understand our bodies as fragments of the universe, as pieces completely detached from the rest, handed over to us

[66] Nelson, J B., & Rohricht, J., (1984) *Human Medicine*, Augsburg Publishing House, Minneapolis, Ch.1.
[67] Nelson. J B., (1992) p41
[68] Nelson. J B., (1992) p44

to inhabit. Rather he proclaimed that the body is the very universality of things. 'My body is not part of the universe that I possess totally - it is the totality of the universe that I possess partially.'[69] In this sense we are part of everything that ever existed and exists now. In viewing the body as fundamentally a machine, René Descartes' strong inclination was to view the earth's body mechanistically, to see neither its organic wholeness nor the deep, connectedness which we all share. By contrast bodily alienation implies that life's very essence or core is rendered other than the earth. I am not part of it, nor is it part of me - we are little more than proximal associates.

In understanding both the givenness of our body realities and the meanings ascribed to them, some way of interpretation that nurtures the greater wholeness of life in relation to the divine, to each other and to the earth is fundamental. Separating ourselves from our very embodiedness is illusory since being detached from the changes, needs and vulnerabilities of the body opposes the possibility of deep connections and the emotional intimacy with others. Revealing our vulnerability enables us to sensitively and imaginatively enter into another's story and empathically to welcome the other into our own. It draws richly on the affective, on the imagination, on the poetic and on the intuitive. Nelson believes 'It is a capacity profoundly linked with body connection and with the bodily revelation which we are in need of. When that capacity in us is alive and well, the presence of the creative and the divine is in us and in our relationships.'[70]

Bodily becoming in a medical setting

All our relationships are mediated through our bodies. Through our emotions we interact with the world. Our senses and bodily integrity ground our relatedness. When the body is deeply alienated, dis-eased, the loss of connectedness to one another, to the world and to the divine is profound. By embracing our suffering as part of being human we become just as alive to pain as to joy. Suffering is shared and carried in the very heart of the universe. In acknowledgement of this shared capacity to embrace it, we are in a sense re-incarnated, healed at the core of our being and as a result re-connected with our personal power, our potential. Then and only then can we live deeply into all parts of our own story and into the stories of others.

[69] Teilhard de Chardin, P., (1968) *Science and Christ*, Harper Collins, New York, pp12-13.
[70] Nelson, J B., (1992) pp96-99

The implications for understanding and reconnecting personal power are immense. In doctor-patient relationships the consequences are significant. Granted that the doctor's authority could be seen as resting within her expertise. It is that all essential trust and faith in the doctor that underpins both patient/doctor relationships and the essence of caring. All too often authority can be read as paternalism and much as paternalism has been frowned upon over the last century and indeed currently, it is interesting to note that as technology advances the risk of paternalism has once more become an issue. Atul Gawande notes that increasing the time devoted to patients can give rise to an even greater chance of authoritarian approaches as the doctor aims to clarify and answer the patients' worries and anxieties, relying as they do on their expertise and medical knowledge rather than an empathetic approach to the patient's dilemma.[71] Paternalism however, erodes faith and trust.[72]

Carter Heyward the feminist theologian suggests that genuine creative authority, sacred at its root, is in our hands. It moves us more fully into 'our body-selves in relation'. It touches and often frightens us as it calls us forth to become more fully who we are already: interdependent and mutual participants in this journey we call life.'[73] It was Hannah Arendt's perception that genuine authority has disappeared in our time because we have 'lost the primordial sources for it' - sources such as faith, belief in a divine presence, in the nation, in marriage, monogamy and politics.[74] From a feminist liberation theological and, moreover ethical point of view, however both external and internal notions of authority are inadequate. Neither is born in, nor gives birth to mutuality as a vital life force that is the substance of love, friendship and voluntary co-operation at all levels of human engagement. When Hannah Arendt suggests that authority has disappeared because the primordial sources for it are lost, she is stating simply that in the mid to late twentieth century, 'we westerners lost our footing. We have nothing to believe in and we are looking in all the wrong places and directions to recover it.'[75]

The experience of authority as organic and encouraging us to be who we are is the antithesis of the more prevalent ideas and experiences of authority as force, coercion or indeed violence. The theologian John E Skinner understood the beginning point of authority as an

[71] Gawande, A., (2014) *Being Mortal*, Profile Books, London, pp187-188.
[72] See Ch.4 p88 of this study for further discussion.
[73] Heyward, C., (1989) *Touching our Strength: The Erotic as Power and the Love of God*, Harper Collins, New York, p73.
[74] Arendt, H., (1968) *Between Past and Future: Eight Exercises in Political Thought*, Viking, New York.
[75] Arendt, H., (1968)

arche, that is, we need an initial reason for authority to experience it as redemptive rather than coercive or damaging.[76] The value and meaning of authority in mutual relation rather is to shape justice. Authority is not a possession, no one of us has it, it is our *dunamis* our dynamic power in relation. The authority of God is not the power to create out of nothing but rather the power to co-create out of the fabric of our daily lives with justice and compassion. According to Heyward, to be creative rather than coercive, real and not rhetorical authority must be shaped in the context of our movement into mutually empowering relationship.[77]

Dietrich Bonhoeffer, the Lutheran theologian, notes that through divine powerlessness and suffering a new kind of power is revealed.[78] Because we have been 'conditioned' into believing that power is one-way, top-down, it is seen frequently as the capacity to influence others while being minimally influenced ourselves and in this way it is both limiting and limited. Such power severely curtails our understanding. But understanding requires vulnerability and reciprocity. The intensity and variety of outlook that can be entertained in the unity of the self without feeling defensive or insecure is liberating. Moreover, it is perfectly within our power to encourage others to become freer in the development of their own diversity and uniqueness; in fact it is fundamental to caring and compassion. Powerlessness so often seen as weakness can be re-interpreted, reincarnated and our faith in life restored. It is the gracious discovery of the communion between the divine and human life in flesh that results in our reincarnation in our becoming, in an awareness of being renewed into the fullness of life.

Control of the body, however develops little understanding of emotional life and when emotions really take hold, they are likely to be overwhelming. When in control of others entering into their subjectivity is almost impossible. By contrast, relational power does not aim to control or diminish the power of another. It is mutual empowerment, willing to be heard as much as to hear the other and to be positively influenced and reinforced by that hearing. Does this hearing result in experiencing more of an acute awareness of our self hitherto unexplored or even unknown, and moreover of the Word made flesh? For Keller if according to the prologue of Gospel of St John 'the word became flesh and lived among us' it

[76] Skinner, J E., (1983) *The Meaning of Authority*, United Press of America, Washington, D.C.
[77] Heyward, C., (1989) p75
[78] Bonhoeffer, D., (1953) *Prisoner for God: Letters and Papers from Prison*, Bethge, E., (ed.), Fuller, R H., (trans), Macmillan Co., New York, pp124-131.

is precisely the word through which all things came into being.[79] And the same verse emphatically clarifies what is far less cited 'What has come into being in the word was life (John 1:4). All of it.'[80] We do not just use words we *are* words, words are distinctive to our bodily reality.

Alfred North Whitehead, the mathematician and philosopher whose work in the twentieth century focused on reality as interrelated processes rather than material objects, believes the very nature of the highest achievement for humankind is to develop empathetic feeling rather than objective rationality since the very nature of the world shows that it is not dualistic but relational. We do not have to retreat from the world in order to understand it, we have to move more feelingly towards it. Whitehead argues the energy that can be scientifically observed in the world is in fact 'emotional intensity entertained in life.'[81] It is this emotional intensity that fuels both the universal drive of evolution and the individual drive for goals. Although we are a distinctive part of the created order we are not detached from the rest of the cosmos. We are in effect co-creators of the universe. Thus all matters are central in creating a future we all share however uncertain that may be. As Whitehead suggests the way to chart this uncertain future is to look for patterns rather than absolute truths beginning with our own experience. Experience mediated through and by the body.[82]

Conclusions

I do not just have a body, I am *my* body. I am always interpreting myself as my body, creating my meanings as my body and using images and language to give significance to my bodily functions and dysfunctions, states of health and disease. When we act on the assumption that our bodies are merely intricate machines suffering is not relieved but rather compounded. We have been led to believe that physicians are responsible, even obligated to relieve suffering, and yet patients continue to suffer not only from their disease but often also from their treatment. Yet the relief of suffering is considered one of the primary ends of medical education, research or indeed practice. The recognition we are more than merely our physical bodies is central to the argument for an approach that reflects the complexity of the human body and critically underpins the thesis in this study. The question lies in what

[79] Keller, C., (2017) *Intercarnations, Exercises in Theological Possibility*, Fordham University Press, New York, p3.
[80] Keller, C., (2017) p3
[81] Whitehead, A N., (1938) *Modes of Thought*, Six Lectures delivered in Wellesley College Massachusetts, and Two Lectures in the University of Chicago, Collier-Macmillan, Toronto, p232.
[82] Whitehead, A N., (1938) p232

health might mean in a wholistic, relational and meaningful sense in comparison with how it is too frequently interpreted, and therefore what effect this will have on any future bioethical perspective. The shift in emphasis away from the traditional clinical approach to the body, to the ways in which consciousness effects the embodied self and equally to the way in which embodiment influences and explains consciousness, is key. What are 'good' reasons for accepting the consequent changes to human embodiment in any medical intervention, to who and what we are, and what may follow as a result?

Bioethics after all was developed to support first and foremost those who could be considered vulnerable to the vicissitudes of a medical practice that frequently leaves them powerless within an environment from which they are distanced by virtue of the specialist circumstances in which they find themselves. How should care and concern for the patient be processed? How is trust between doctor and patient to be rekindled and power and authority to be negotiated? These issues are fundamental to any exploration involved in creating any dynamic approach. Both patients and physicians co-operatively need to make critical decisions about life-changing medical interventions. This process requires sensitivity on the part of the patient *and* the medical professionals, strengthened by a much greater awareness of what it means to be humanly embodied. It means an intense focus on listening, watching intently, understanding and interpreting faithfully the signs of the body and responding not just to the vital signs and 'the case history' but to the wider effects that illness and disease impose on the patients' as well as on the professionals' everyday lives. Because the medical professional too as listener and co-coordinator of the outcome of their expertise is co-creator of their own healing mediated through the story and subsequent caring for and healing of the patient. As Rita Charon professes 'I feel honoured to have found some fresh approaches to routine clinical work, because these new ways of being a general internist *add* to my pleasure in being a doctor…the practices [of narrative medicine]…have renewed me and given me added joy.'[83] It seems that the onus is on the clinician therefore to engage at a meaningful level empathising with the patient's voice that is so important in creating the healing of both doctor and patient in order to contribute to a better informed, more fulfilled, co-operative purpose that adds greater clarity to a moral/ethical outcome.

In sum, Bernard Williams commented: even if ethical norms cannot be directly deduced from scientific research, the only way a conceivable ethics could be developed is by starting with

[83] Charon, R., (2006) *Narrative Medicine: Honoring the Stories of Illness*, Oxford University Press, New York, p197.

an investigation and analysis of human nature.[84] That the world of human being is undeniably a world of meaning and ethics is clearly part of this sphere of analysis. Chapters, 6, 7 and 8 argue ethics through a care-centred, multi-vocal approach by way of narrative that addresses the dynamic nature of the individual and their illness. But firstly Chapter 2 explores the nature of human being in order to expand on the ideas discussed in the Introduction and Chapter 1.

[84] Williams, B., (1985) *Ethics and the Limits of Philosophy*, Harvard University Press, Cambridge, Massachusetts, pp154-155.

Chapter 2

Thinking through the Body

The common division of the world into subject and object, inner world and outer world, body and soul is no longer adequate.[85]

Werner Heissenberg

Introduction

The main theme of this chapter is to address the body and its complexity from a different perspective. So much concentration on the lack of organs for transplantation and the push to reach very difficult national UK donation targets and transplantation rates within extreme financial constraints has diverted attention away from the prime rationale for undertaking transplantation in the first place.[86] It seems inconceivable to be 'tinkering' with the body devoid of a deeply considered discussion of what 'body' actually means in order to develop a different ethical approach to support those who undertake such 'tinkering' and those who would be 'tinkered' with.[87] In short, what is meant by the body should surely be of central importance.

The links between the body as a structure, as energy, indeed as quantum concepts of particle and wave will be developed and discussed. That is the body as inextricably connected at a profound level with all that exists. Once argued, I believe that this will serve

[85] Cited in Davies, P., (1983) *God and the New Physics,* Simon and Shuster, New York p112.
[86] NHS Finance, Mackey urges 'hard focus on winter plans as trusts face financial struggle', National Health Executive, www.nationalhealth executive.com/NHS-finance, accessed 04/09/2017.
[87] Sharp, L A., (2014) *The Transplant Imaginary: Mechanical Hearts, Animal Parts and Moral Thinking in Highly Experimental Science*, University of California Press, Berkley and Los Angeles, p113.

as a metaphor for the faith, hope, trust and love which I understand to underlie the body's own power and capacity for healing both sickness and suffering, motivated by an awareness of what it means to be ill seen through the lens of the patient's story. Whilst I don't believe that narrative of whatever form is the complete answer to the problems encountered in using such a narrowly focussed and static bioethical framework as Principlism, I do think that story in whatever form is valuable as a stimulus for deeper discussion of the issues relevant to the patient-doctor encounter, since it is a living, dynamic snapshot at the time of the patient's unfolding of their illness. In any case I argue that narrative *per se* has an important place in opening out the difficulties faced by those involved in any delicate area of decision-making.[88]

The body and its meaning

Blackman talks about 'a body' not as a singular, bounded entity or substance but rather as what she terms 'the body multiple.'[89] She argues that the body is not enclosed by the skin, where skin is to be understood as a kind of container for the self, but rather our bodies always extend and connect to other bodies, human and non-human, to practices, techniques, technologies and objects which produce different kinds of bodies and different ways of enacting what it means to be human. In direct contrast to the narrow view taken by Beauchamp and Childress who maintain that the language of personhood is too unclear to 'resolve the problems of moral status',[90] Blackman seeks to demonstrate the dynamic nature of human being which embodies potential both complex and relational. The idea of the body as simply something that we *have* and *are* is displaced as the focus shifts to what bodies can *do*, what bodies could *become*, what practices enable and coordinate the doing of particular kinds of bodies, and what makes this possible in terms of our approach to questions about life, humanness, culture, power, technology and subjectivity. These represent some of the themes that radically reconstruct the idea of the body as substance or entity and we might say as distinctly human.

The reformulation of the perceptions of body and bodies across the humanities has also demanded an imaginative re-engagement with ethical method. If the body is not simply a

[88] Examples include: who should receive an organ or not; the vital physical and emotional support through the process and after the surgical procedure for the transplant patient as well as the donor and support for those whose chances of an organ are extremely limited.
[89] Blackman, L., (2008) pp1-3
[90] Beauchamp, T L., & Childress J F., (2013) pp67-68

natural body - often seen as the rightful province of the life and biological sciences - then how can bodies be examined and interrogated through frameworks that have been understood as less inclusive and thereby less wholistic? As Aristotle suggested 'the whole is greater than the sum of its parts.' [91] Thus a way of accounting for and creating awareness of such bodily wholeness is paramount. The concept that 'the whole is more than the sum of its parts' thus holds, for when the parts are integrated within the living organism, properties emerge and processes take place that are not the simple sum of the properties of those parts. Laszlo argues that the living organism cannot be reduced to the interaction of its parts without losing its 'emergent properties' - the very characteristics that make it living.[92]

What does it mean to think through the body from within our own bodies as well as within a specific discipline such as the medical sciences, for to 'think through the body' is a noticeably broader notion. It requires critical reflection on how different perspectives enable us to approach the body in order to gain a fuller picture of what 'body' means. How might we embody our own sense of subjectivity for instance? We may feel that our sense of who we are is an amalgam of our physicality, biological processes and our place and position as particular kinds of social subject within diverse cultural milieux. Indeed one of the problems central to the challenge to 'think through the body' is exactly how processes can be brought together that have traditionally been viewed as separate elements. Imperative however is that we move beyond thinking of bodies as substances, as special kinds of things or entities, but rather to explore bodies as sites of potentiality, process and practice.

The body as energy

Kinesiology is one such practice that focuses on the subtle body and treats it as a series of energy flows that are equally considered the sites of our power, a power that motivates healing. The therapy is informed by ancient traditional views demonstrating the importance laid on esoteric anatomy that has found its place in such current alternative perceptions of the body as evidenced by complementary medicine and therapies, including Yoga, Acupuncture, Chinese Medicine and Ayurveda. Such therapies emphasise the importance of balancing and maintaining energy flow within the body as vital for bodily health and the relief of suffering.

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[91] Heidegger, M., (1995) *Aristotle's Metaphysics Θ 1-3 on the Essence and Actuality of Force (Studies in Continental Thought)* First Thus Edition, Indiana University Press, Indiana.
[92] Laszlo, E., (2006) *The Chaos Point*: *The World at the Crossroads*, Piatkus Books, London, p92.

According to Mircea Eliade one of the earliest *Vedic* identifications that became central in all later Indian esoteric traditions is that between the body and the universe.[93] One of the key texts, a late book of the *Ṛg Veda* the *Puruṣa Sūkta* which is often quoted throughout the Hindu tradition is a famous hymn of cosmic man. The hymn shows if the cosmos is in some sense sacred then so is society that manifests itself in a hierarchical order, an order that is also reflected in the structure of the body. The scale of this order is identified as the purity or pollution associated with the body: the head, as the highest part of the body is the purest and the feet, the lowest part is the most polluted. Social and individual bodies are reflections of each other and both are part of the larger structure or body of the cosmos. Gavin Flood argues that this integration of society and cosmos, of body and society was the sacred order of the universe. As a sacred order it is eternal and unchanging brought to life in *Vedic* ritual, expressed in the hymns and clarified in texts of ritual exegesis.[94] The material human body therefore in *Vedic* times was thought to be a gross manifestation of a subtle body, which in turn is a manifestation of a supreme body. In other words understanding the nature of humanity through a wholistic lens was considered fundamental.

The subtle body

In certain eastern traditions, it is believed that extending and interpenetrating beyond the physical body are several subtle energy bodies of the human form. Unlike our physical form these are not detectable by the five senses. However, many subtle effects can be measured that appear to have no physical source, the healing energy of a healer's hands is one such example.[95] Once subtle bodies are incorporated into the physical body, the complexity of the human form becomes evident, in other words visible. In essence the subtle energies associated with the physical form are well defined.[96] Such complexity is shown in **Figure 1**.[97] The subtle body comprises several layers - popularly known as the auras. While each layer

[93] Eliade, M., (1937) Cosmical Homology and Yoga, *Journal of the Indian Society of Oriental Arts*: **5:37:188-203**. The *Vedas* are considered the earliest literary record. They examine the nature of the universe. Hymns, rituals, legends and magic were handed down orally to an exclusive male line – *brahman* – who were trained as priests from childhood as disciples of *gurus* and exhorted to maintain the accuracy of the texts in order to preserve their purity. In fact the *Vedic* texts were only written down after many thousands of years, an act that was considered both polluting and sacrilege.

[94] Flood, G., (1996) *An introduction to Hinduism*, Cambridge University Press, Cambridge, p188.

[95] By *Kirlian* photography for instance. Although much debated, Kirlian believed that images created by Kirlian photography might depict a conjectural energy field, or aura thought, by some, to surround living things. Kirlian and his wife were convinced that their images showed a life force or energy field that reflected the physical and emotional states of their living subjects. They thought that these images could be used to diagnose illnesses. In 1961, they published their first article on the subject in the Russian Journal of Scientific and Applied Photography.

[96] Judith, A., (2004) *Eastern Body, Western Mind: Psychology and the Chakra System as a Path to the Self,* Random House, New York.

[97] The diagram for **Figure 1** is from https://uk.images.search.yahoo.com

extends beyond the lower, it does not exist just as a layer in isolation around the body, but rather penetrates all the layers below it, and then extends further from the physical body to the wider systems within the cosmos.

Interpenetrating and surrounding the physical body, the etheric body also known in Sanskrit as the *Annamaya Kosha* is the densest of all the subtle bodies. Being closest in vibration to the physical body, it holds a subtle replica or etheric double of every organ in the body and of the body itself. Interestingly the etheric aspect of an organ does not withdraw from the body when the physical organ is removed, *at this level memory traces remain*.[98] In sum, the etheric body forms a primary interface between the electromagnetic energy flows of the physical body and the subtle energy flows of the other bodies.

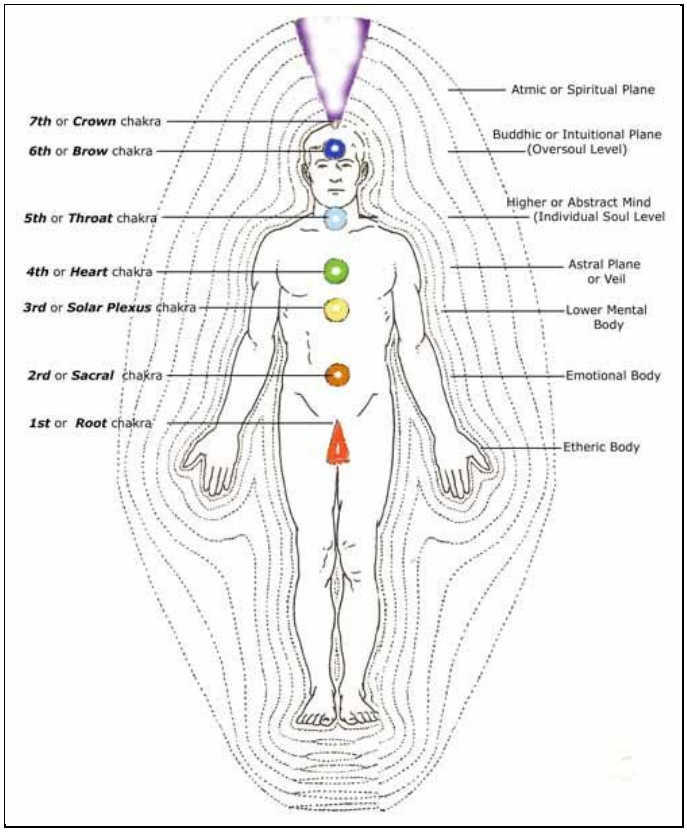

Figure 1: The subtle body – the auras

Beyond the etheric body is the astral body the *Pranamaya Kosha* which is the realm of the emotions. Here emotions exist as vibrational patterns that are believed to interface with the limbic brain. This is thought to occur via stimulation of the electro-chemical/magnetic energy within the nerves in the survival centre of the brain, the amygdala, which is

[98] White, R., (1998) *Chakras: A New Approach to healing your Life*, Piatkus Books, London, p11. Such an analysis is significant for later discussion of the effects of organ transfer.

responsible for the control of the 'fight and flight' response. The next layer, the astral body is the mental body, the *Manamya Kosha*, consisting of higher and subtler vibrational energies, considered to be the realm of thoughts. Here the self or ego becomes manifest, and the intellect expressed. Like the other subtle bodies, the mental body equally has several layers. The lower mental body is concerned with mental images obtained from direct sensory experience of and reasoning within the objective world. At the lower mental level the vibrational patterns are translated into action through conscious intent. Higher abstract reasoning and conceptualisation occur at the higher mental body. Interrelating with the astral body to transfer/translate thoughts into feelings, the higher mental body is the layer where transcendent emotions are stimulated. Emotions such as acceptance, compassion, empathy, unconditional love and forgiveness, become manifest at this plane. The causal body, *Anandamaya Kosha*, interpenetrates at the highest of subtle vibrational energies. This layer is the realm of the spirit, or higher self and connection to the divine. It deals with the essence of things and is thought to be the true cause that lies behind the illusion of appearance, it is also the plane of devotion, of connecting with universal consciousness. At the level of the mental body the self is manifested. At the level of the causal body the oft-called 'soul' or inner self is experienced, and the limits of physical time and space disappear.

The auras are one way of accessing the body at the invisible level. They signify the difference between pain and suffering, an important distinction I will be making later in the chapter discussing narrative. The consequent loss of information for conflating pain and suffering is critical if we are to understand with any degree of confidence that the path taken to navigate through the decision-making process for any patient, donor and recipient is indeed appropriate pre- and post-surgery. Equally relevant for transplant medicine is the observation that 'memory traces' remain even when an organ is removed and so heritage plays an important role for those donating an organ and for patients who experience some strange and puzzling characteristics of themselves after transplant.[99]

Within certain yoga traditions the spiritual body is understood as the causal body since it is believed that what occurs in the physical body originates here - it is considered the 'true cause' of what is experienced.[100] Thus at the causal level vibrational thought patterns are generated, which in turn stimulate astral states of emotion, which then generate etheric

[99] See Sharp, L A., (2006) *Strange Harvest* and (2014) *The Transplant Imaginary*, and Sylvia, S., & Novak, W., (1997) *A Change of Heart*.
[100] See the analogies in the *Upanishads* for instance in Easewaran, E., (1987) *The Upanishads*, Arkana, London.

patterns of *pranic* flows[101] and patterns of *ch'i* which then become translated and transferred into the physiological and physical states of the body.[102]

Ch'i and the meridians

According to Ted Kaptchuk, the idea of *ch'i* or *Qi* as it is frequently seen in texts, is fundamental to Chinese medical thinking.[103] It is said that everything in the universe, organic and inorganic, is composed of and defined by its *ch'i*. But *ch'i* is not some primordial, immutable material, nor is it merely vital energy, although the word is occasionally translated in this way. In ancient Chinese philosophy, matter and energy are not distinguishable, *ch'i* can be considered as matter on the verge of becoming energy, or energy at the point of materialising. *Ch'i* is perceived functionally in Chinese medicine by what it does: it is the source of all movement including heartbeat, walking, aging, rejoicing, speaking; it protects the body from disease; it is the source of harmonious transformation such as transformation of the products of the digestion system into other substances: tears, blood products, sweat; it governs retention of the organs of the body in their proper place and prevents the loss of various bodily fluids and it regulates the body's temperature depending on circumstances.[104]

The Chinese recognise 14 major meridians or vessels with their own unique points that distribute *ch'i* around the body. 12 vessels are bilateral, with one running up or down the right and one up or down the left side. A further two run centrally over the front and back of the body.[105] These 14 meridians are called the cardinal or primary meridians, but they represent merely the most obvious of all energy flows within the body. Each of the major meridians has a number of specialised points that regulate and direct energy flow through the pathways by interconnecting the meridians via myriad smaller vessels of varying size. The secondary vessels then connect to various aspects of bodily function. So for each meridian, rather than a straight line flow of *ch'i* there is a web or orb of interconnecting energy pathways connecting each meridian with every other meridian in the body. The Chinese envisioned the meridians to be grouped into Five Elements, each element being a

[101] Put simply, in Hindu philosophy *prana* is understood as life force/energy, and *ch'i* is the Chinese equivalent.
[102] Much of the information for this section was researched from: White R., (1998), Krebs, C T., & McGowan, T., (2014) *Energetic Kinesiology: Principles and Practice*, Handspring Publishing, East Lothian and Sivananda Yoga Vedanta Centre, (1996) *Yoga Mind and Body*, Dorling Kindersley Ltd., London.
[103] Kaptchuk, T J., (1983) *Chinese Medicine: The Web that has no Weaver*, Rider, London, p35.
[104] Kaptchuk, T J., (1983) pp36-38
[105] Krebs, C., & McGowan, T., (2014) pp43-46

coupled pair - one being a yang meridian and the other a yin meridian.[106] Each element representing a primary quality with the 5 qualities: earth, fire, metal, wood and water and in addition those five elements themselves being linked by the energy flow of *ch'i*, shown in **Figure 2**:[107]

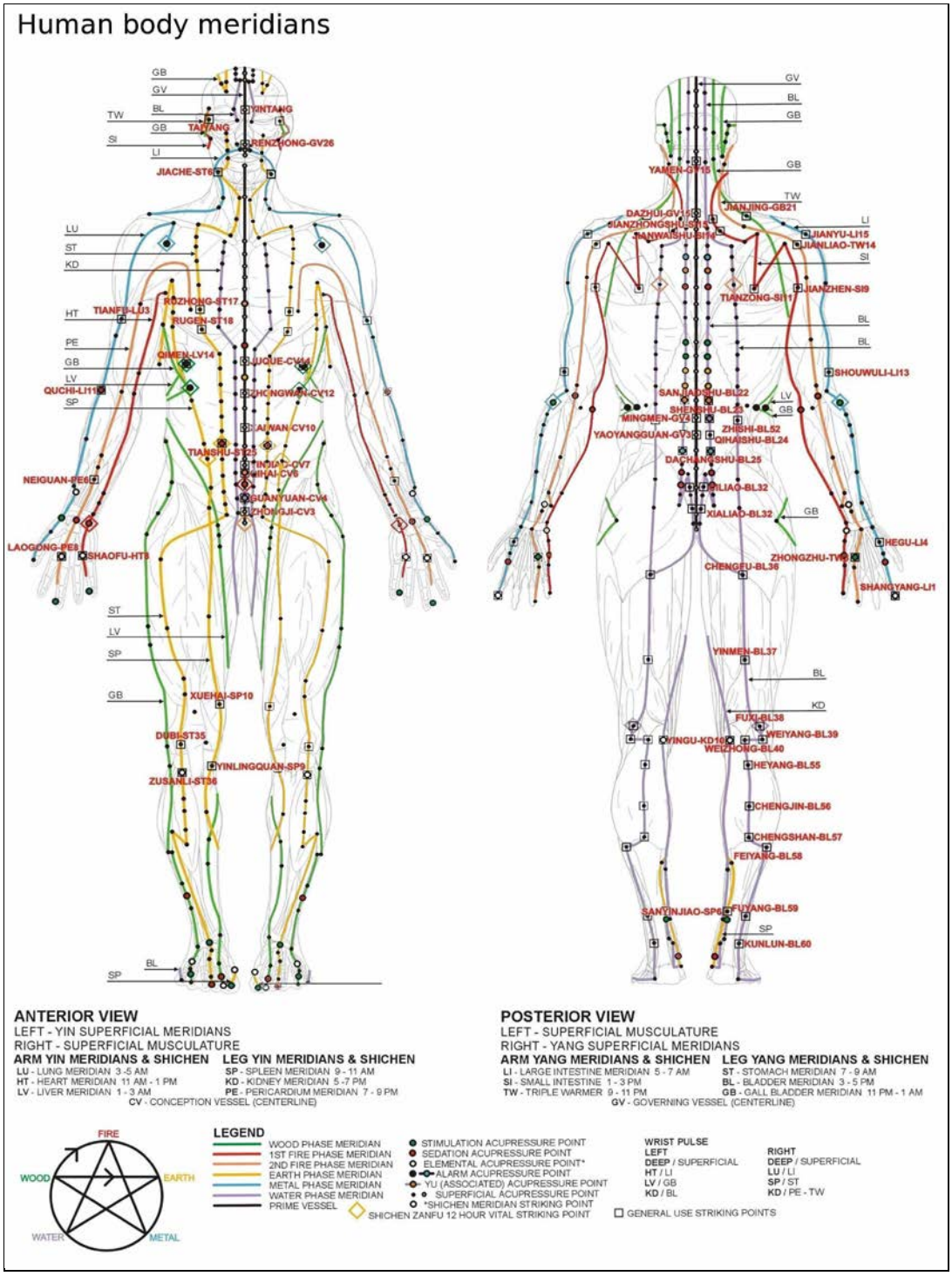

Figure 2: The meridians

[106] Yin and Yang really represent a way of thinking in which all things are but part of a whole. No one thing can exist in and of itself.

[107] **Figure 2**: The salient points of the meridian system are detailed here. For an in-depth study, see Krebs, C., & Brown, J., (1998) *A Revolutionary Way of Thinking*. The diagram is from https://uk.images.search.yahoo.com

According to Kaptchuk [108] the Chinese Meridian System dating back to around 2500 BCE has suffered adverse comments along with many other alternative therapies. Some commentators see it as 'hocus-pocus - the product of primitive or magical thinking.' If a patient is helped by means of herbs or acupuncture, they see only two explanations, either the positive results were psychosomatic or it was the 'happy result of a hit and miss pin-sticking exercise.'[109] In fact Chinese medicine considers important certain aspects of the human body that are not significant to Western medicine. At the same time Western medicine observes and can describe aspects of the human body that are insignificant or not perceptible to Chinese medicine. For instance Chinese medical theory does not have a concept of the nervous system. Nevertheless Chinese medicine can be applied in cases of neurological disorder. Equally use of certain terminology is seen as strange to the Western ear. The Chinese for instance often refer to some diseases as being generated by 'dampness', 'heat' or 'wind'. The perceptions of the two traditions reflect two different worlds, but both can heal the same body.

The Western physician starts with a symptom, searches for the underlying mechanism - a precise cause for the specific disease. Whilst the disease may affect various parts of the body, it is a relatively well-defined, self-contained phenomenon. Precision in diagnosis frames a quantifiable description of a narrow area. The physician's logic by the same token is analytic, 'cutting through the accumulation of body phenomena like a surgeon's scalpel to isolate one single entity or cause.'[110] The Chinese physician in contrast, directs attention to the complete physiological and psychological individual. All relevant information including symptoms as well as the patient's other general characteristics are gathered and woven together until it forms what Chinese medicine calls 'a pattern of disharmony.'[111] This pattern of disharmony describes a situation of 'imbalance' in a patient's body. The question of cause and effect is secondary. It isn't a case of the cause of the problem, but rather the relationship between the symptom and its cause. Discerning the relationships among bodily events occurring at the same time become the interesting features. It is the patterns of disharmony in both the patient and their link to the universe that consequently guide the framework for treatment.

[108] Kaptchuk, T J., (1983), pp1-2
[109] Kaptchuk, T J., (1983) pp1-2
[110] Kaptchuk, T J., (1983) p4
[111] Kaptchuk, T J., (1983) p4

To understand the patterns of the universe it is helpful to turn to quantum physics. Such concepts that find expression in the further splitting of the atom to constituents such as particle and wave, are currently believed to be inextricably linked to the behaviour of matter both organic and inorganic in the entire cosmos. For as Whitehead suggests, twentieth century quantum concepts have something relevant to say about universal phenomena as wholistic which will make significant inroads into *linking entities* previously considered as discrete.[112] And the American feminist theorist and quantum physicist Karen Barad posits that 'matter and meaning are not separate elements.'[113] We ignore the microcosmic matter of the universe at our peril for as quantum concepts reveal the quantum non-location of the particle - the unknowing - opens us out to the understanding that each is in each and all is in all. Such a position resonates with all that has been discussed so far giving further substance at a scientific level, to the concept of incarnation, and to the wholistic, relational and fluid body as discussed in Chapter 1 and furthermore to the discussions in subsequent chapters in this study. Additionally, quantum ideas add depth and clarity to the mappings outlined above in revealing that when power and potential are inhibited, the interruption to the flow of the subtle body results in disharmony, imbalance and the profound effects of suffering that long-term manifest as pain.

The body and quantum concepts

I believe in one matter-energy, the maker of things seen and unseen.[114]

Jane Bennett

The classical view of nature began to crumble at the end of the 19th century when the basic building blocks of the universe turned out not to be basic after all. The supposedly indivisible atom, of which all things in the world were said to be constructed, proved fissionable into a bewildering variety of components. The elementary particles themselves dissolved in a swirl of energy. It was Max Planck who discovered that light, like all energy, comes not in a continuous stream but in discrete packets of bound energy called quanta that refuse to behave like common-sense objects. It appears that the behaviour of particles that carry light, matter and force until registered by an instrument of detection or another act of observation, have no specific position, nor do they occupy a unique state. Ultimate units of physical reality then have no uniquely determinable location and they exist in a

[112] Whitehead, A N., (1938) p232
[113] Barad, K., (2007) *Meeting the Universe Halfway*, Duke University Press, Durham, North Carolina, p3.
[114] Bennett, J., (2010) *Vibrant Matter: A Political Ecology of Things*, Duke University Press, Durham, North Carolina.

superposition of several potential states at the same time. Laszlo points out that the most amazing feature of quanta is their subtle but constant and apparently space-time transcending interconnection. Thus the fundamental units of the physical world prove to be intrinsically and instantly entangled with each other - and that of course includes us.[115]

Once two or more quanta enter the same state, they remain instantly linked no matter how far they may be from each other. So when experiments on twin particles in a so-called single state are conducted and their spins cancel each other out to yield a total spin of zero, a strange thing happens. No matter how far the twin particles are separated, when one of them is measured, the measurement on the other corresponds precisely to the results obtained from the first - even though the result could not have been determined in advance. It is as if the second particle 'knows' what is happening. The information that underlies this knowledge appears to be conveyed over any finite distance and at the speed of light. According to Laszlo, non-locality tells us that all things in the world are interconnected, and all are part of more integrated ensembles known as wholes.[116]

So it is that matter, at least at quantum levels undergoes a deconstruction. As David Bohm puts it: an atomic particle might at best be described as a poorly defined cloud, dependent for its particular form on the whole environment including the observing instrument.[117] In a medical situation for instance, the patient who comprises electrons, protons, neutrons and so on is dependent on the doctor's observation/perception - rightly or wrongly. It turns out however while light waves were really appearing as particles, particles were also really appearing as waves. Laszlo comments: this is the province of Bohr's theory of complementarity.[118] What is happening within these seemingly contradictory appearances? Well it depends on how you measure it. It depends on your perspective. Unlike the particle however, waves by their very nature are not encountered singly but in their lapping and overlapping each other. In overlapping which is to say interfering with one another, waves add together to form 'superpositions' - structures transcendent of classical 'positions.' Such entanglement forms what is understood as the quantum vacuum - a void that is actually a virtual sea of power and potential.

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[115] Laszlo, E., (2006) p90
[116] Laszlo, E., (2006) pp90-91
[117] Bohm, D., (1985) Fragmentation and Wholeness in Science and Religion, *Journal of Religion and Science*: **20:2:125-133**
[118] Laszlo, E., (2004) *Science and the Akashic Field: An Integral Theory of Everything*, Inner Traditions, Vermont, p71.

Could it be therefore that superpositions represent our ignorance? Barad is quick to point out, not in the sense of our failure to know a classical object that is somehow hidden from us.[119] Rather superpositions represent ontologically indeterminate states - a sea of possibilities. As Keller implies, the mystery lies not in unknowability alone, but in the intra-activity - the relationality that suspends the very notion of a thing as a bounded body or classical object. The uncertainty expresses and explains an 'ontological indeterminacy.'[120] What we are dealing with here is an open-system, a fluid and flexible relationality constantly overlapping and dynamic.

Quanta are not unconscious matter. They stem from the basic constituents of the complex fields that underlie the cosmos, and they are not unlike the qualities we associate with consciousness. The atomic physicist Freeman Dyson has pointed out even elementary particles are endowed with a form and level of proto-consciousness.[121] Conscious matter at a lower level of organisation, the neurons in the brain for example, generate conscious matter at a higher level of organisation in the brain. In affirming that *physic* and *psyche* evolved together, reality is not reduced to structures made up in themselves of inert and insentient material building blocks nor is reality assimilated to a qualitative nonmaterial mind.[122] We take both matter and mind as fundamental elements of reality but unlike dualism, there is no separation, merely different aspects of that same fluid reality. Our reality. Indeed Dyson proposes that: 'Matter in quantum mechanics is not an inert substance but an active agent, constantly making choices between alternative possibilities.'[123] Thus the so-called proto-consciousness of the quantum vacuum becomes localised and articulated, as particles emerge from it and evolve into atoms and molecules. On life-bearing planets they evolve further into cells, organisms and ecologies. The human mind associated with the highly evolved human brain is a high-level articulation of the cosmic consciousness, emerging from the vacuum that infuses all things in space and time. This 'absence' or quantum vacuum is similar to that described as the Tao or the Void in many Taoist, Buddhist and Hindu texts. In the words of the Tao Te Ching 14:

[119] Barad, K., (2007) p265
[120] Keller, C., (2015) pp140-141
[121] Dyson, F J., (1988) *Infinite in all Directions*, Harper & Row, London, p297.
[122] Laszlo, E., (2004) *Science and the Akashic Field: An Integrated Theory of Everything*, Inner Traditions, Vermont pp146-148.
[123] Dyson, F J., (1988) p297

Look, it cannot be seen – it is beyond form.
Listen it cannot be heard – it is beyond sound.
Grasp, it cannot be held – it is intangible.
These three are indefinable,
Therefore they are joined in one.

From above it is not bright;
From below it is not dark:
an unbroken thread beyond description.
It returns to nothingness.
The form of the formless,
The image of the imageless,
It is called indefinable and beyond imagination.

Stand before it and there is no beginning.
Follow it and there is no end. [124]

The Tao Te Ching illustrates the different philosophies emanating from Eastern traditions. In those traditions as in quantum field theory of twentieth century physics, emptiness has a kind of pregnant fullness and stillness is witness to truth. Things, existence, the self, the body are held together by a permeating centre that cannot itself be seen or expressed. The self cannot be lived or understood except in terms of the whole of creation that I experience as 'I'.[125]

Quantum concepts and matter

For Barad scientific practice in quantum concepts reveals not what is already there, rather what is disclosed is the effect of 'the intra-active engagement of our participation within and as part of the world's differential becoming. Not pre-existent but dis-closed, opened out into its concrete actuality, a co-incident of becoming.' Matter comes to life 'it feels, converses, suffers, desires, yearns and remembers.'[126] Each wave spreads literally everywhere. It is in effect, infinite, boundless, it spreads continuously but heterogeneously, and its potentiality is not merely a mathematical abstraction. This potentiality exists in order that we come to terms with ourselves and with our actions. Indeed we need to draw 'this pragmatic anthropocentric theory as a useful distillation from an underlying non-anthropocentric structure' as the quantum physicist Henry Stapp insists, such an ontology 'places the evolution of our conscious process within the broader context of the structure of nature

[124] Lao Tsu, *Tao Te Ching*, (1972) Gia Fu-Feng and English, J., (trans), Gower Publishing, Aldershot.
[125] Lao Tsu, *Tao Te Ching*, 1972
[126] Barad, K., (2007) p361

herself.'[127] Like Laszlo, he argues that every electron incorporates mental aspects into the process of the creation of reality. Each event unfolds with a certain awareness. So for each event that unfolds as an operation of the literally boundless relations that form the potentiality of the moment, we - that is humanity, have some responsibility.[128]

The wave materialises as a particularity - that is as any quantum particle. Such a discrete emergence exemplifies Whitehead's 'actual occasion of experience.' Thus the actual individual - yourself or one of your innumerable electrons - takes place as an actualisation; there is no enduring identity of matter or of you; there is only materialisation in this moment. Each particularity is a distinct re-composition of its world. Whitehead maintains there is thus 'a becoming of continuity, but no continuity of becoming.'[129] The continuity of such a process is not then of a substance but of the past flowing in waves of potentiality out of which this present becoming actualises. The past comprises our relations to what has already become, and so becomes the potential for our future becomings.[130]

We have established that when two particles originally linked and then experimentally separated fly off in opposite directions, they remain immediately responsive to one another - no matter what the distance. They remain entangled. Thus entangled particles, even though spatially separate do not operate autonomously. This is not simple randomness, it is indeterminacy enfolded in interdependence: non-knowability and non-separability get together - instantly at any distance. Such a connection takes place because both events form a single creative act, they seem to feel each other - a single actual entity arising out of a common field of potentialities. Contrary to some belief that an object over there does not care about what you do to another object over here, John Bell's experiments have shown that an object over there *does* care about what you do to another object over here.[131] What any creature is cannot be determined in separation from its formative relations. And the lack of discrete entities according to quantum understanding works at any distance whatsoever. It turns out that these inter-linkages that take place across any distance are just what many people mock as telepathy. Sheldrake has written extensively on a similar notion that he terms morphic resonance, a concept he exemplifies in his book *Dogs that know when*

[127] Stapp, H P., (2009) Quantum Collapse and the Emergence of Actuality from Potentiality, in *Process Studies*: **38:2:339**
[128] Stapp, H P., (2009) **38:2:339**
[129] Whitehead, A.N., (1978) *Process and Reality*: *An Essay in Cosmology*, corrected edition, Griffin, D R., & Sherburne, D W., (eds.) Free Press, New York, p35.
[130] Whitehead, A.N., (1978) p35
[131] Bell's experiment in 1964 of the non-locality of particles in his book *Speakable and Unspeakable in Quantum Mechanics*, Cambridge University Press, Cambridge, published in 1987.

their owners are coming home.[132] In other words the moment to moment becoming of each creature, each actual entity, suggests something quite other than - as Keller humorously proposes 'the creation of increasingly "beefy beings" from an original void who then move discretely about within a relative emptiness. The dizzying - chaosmic - alternative might translate poetically into the *creatio ex profundis* in which every creature emerges moment by moment from a wavy boundlessness.'[133] It could be said that if the metaphor of divine entanglement in the world begins to arise in the connection between theology and science it is only because matter takes on a new meaning through the lens of quantum concepts.

According to Bohm '[A] centrally relevant change in descriptive order required in quantum theory is the dropping any notion of analysing the world into relatively autonomous parts, separately existent but in interaction.'[134] So whether moving upward or outward or down into smaller and smaller units, we do not come to fundamental units, or indivisible units, but we do come to a point where division has no meaning. It may be that in some sense each unit contains a total structure enfolded within it. As a metaphor for this enfolding process Bohm likens it to a hologram where each region of the hologram makes possible an image of the whole object, an object which could be more sharply defined as well as containing more points of view.[135] The process in which the order in the hologram becomes manifest to the viewer in an image is called unfoldment or explication. For him explicate and implicate orders complement each other at every level. This he suggests accords with Nicholas of Cusa for whom the explicate order signifies the manifest multiplicity of the universe. The explicate will be constantly an expression of what is otherwise enfolded.[136] Waves from each point unfold but at the same time waves from many points are enfolding to give rise to a new wave front and so each process includes both an enfolding and an unfolding. It is only when we focus on one part of the process that we are led to talk of these as distinct, as dualisms.

Turning aside from Cartesian dualism means that what we experience as independent movement through various levels of subtlety, will in a natural way ultimately move the body

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[132] Sheldrake, R., (2000) *Dogs that know when their owners are coming home: and other unexplained powers of animals*, Arrow Books, London.
[133] See Keller's interpretation of the chaotic and watery beginning of the universe in her book *Face of the Deep*, (2003).
[134] Bohm, D., & Hiley, B J., (1993) *The Undivided Universe: An Ontological Interpretation of Quantum Theory*, Routledge, Abingdon, pp352-353.
[135] Bohm, D., & Hiley, B J., (1993) pp352-353
[136] Nicholas of Cusa, (1997) *De docta ingnorantia*, in *Nicholas of Cusa: Selected Spiritual Writings,* Bond, H L., (trans), Paulist, New York, p140.

to the level of the quantum vacuum and the sea of potential. In some sense within the implicate order is an implication that a rudimentary mind-like quality is present even at the level of particle physics, and as we go to subtler levels, this mind-like quality becomes stronger and more developed. The model thus evades dualistic relation or materialist reduction. This subtler layer implies that the universe is flooded with animated awareness, matter comes to life, a life in all its fullness. Thus for Bohm through enfoldment each relatively autonomous level of mind participates in the whole to one degree or another. Connectivity is unfolded inseparably from all that comes enfolded in each particular fold, each particle, each singularity.[137]

In a universe of incompletion, quantum indeterminacy destabilises the entire apparatus of substantial matter and its metaphysics. Whitehead articulates the challenge at the quantum level where 'mere endurance' which characterises the 'undifferentiated sameness' of substance, collapses into the vibratory streaming of energy.[138] In the modern answer to the question 'What is nature made of?' Whitehead answers that it is couched in terms of 'stuff, or matter or material - the particular name chosen is indifferent - which has the property of simple location in space and time…What I mean by matter or material, is anything which has this property of simple location' thus matter is present in a simple sense that 'does not require for its explanation any reference to other regions of space-time.'[139] Yet numerous years later Whitehead changed his mind and wrote an entire alternative to materialism and matter, notions that in his view seemed fundamentally frozen into both dualisms and monisms of substance. He called this the philosophy of organism, in which every creature or actual entity including most expressly all those traditionally called inorganic, an 'event of interrelation.' A live event, an actual occasion of experience; it 'feels', it 'prehends' - usually with no consciousness - the world from which it comes, the world of which it becomes. Every quantum of energy is thus metaphorically describable as a 'throb of emotion' or a 'subject of experience', a 'vibratory organism.'[140] Such a subject is not describable as an enduring entity unfolding in time, having experiences and attributes, but an occasion of becoming in relation. Far from simply located, every event is in its uniqueness here and now involved in one way or another prehended in every other. The singular perspective in space-time is a momentary decision - it does not establish any boundary of mere non-relation to anything.

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[137] Bohm, D., & Hiley, B J., (1993) p352-353
[138] Whitehead, A N., (1925) *Science and the Modern World: Lowell Lectures 1925*, Free Press, New York, p35.
[139] Whitehead, A N., (1925) p35
[140] Whitehead, A N., (1925) pp175-176

Likewise, Keller believes that matters of fact, matters of concern, matters of care are shot through with one another, and God the symbol of that mattering, however over-abstracted, cannot be dislodged from matter. Thus narratives of creation, incarnation, bodily resurrection 'did not await science to conceptualise their own actions.'[141] Quantum relationality turns the creation into such a mysterious relational field as to make an intimate relation to its source believable. If that creative source is no longer conceivable as producing a world and directing it to its end, we could imagine it as unfolding in and through that world, as in its own flesh, and moreover as welcoming the indeterminate emergence of finite bodies with creativities all their own. In a creation in which the boundary between inside and out is an imposed abstraction, whether for care or for convenience, the difference between creator and creation must remain non-separable.[142] As Bohm says 'one could say that through the human being the universe is making a mirror to observe itself.'[143] The seeing of God is not the seeing of the universe, but since God is not an object of vision, the universe seeing itself in our eyes may signify just what in our verbal icons we have called the 'vision of God.' Or as he suggests, 'the universe could be regarded as continuous with the body of the human being.' The universe in each creature *is* that creature.[144]

The actual boundaries of bodies are never static, they are in states of constant flux. This process of flux and exchange must come to mean something other than an absolute beginning or end. Incarnation, divine multiplicity or real divinity is necessarily characterised by this becoming porous and interconnected in the world. According to Laurel Schneider, bodies whether of humans or stars are always in a state of exchange. They are porously open to each other. Boundaries do exist but they do so temporally and spatially - they are always in a state of emerging or passing away. Incarnate, divine being therefore resists singularity just as all bodies resist singularity.[145] The more closely you look at any body, culture or language or indeed religion, boundaries blur. Since human beings are related to every other creature through the energy that flows into and through them, boundaries between entities are therefore proximal, creative, and temporary. In turning to the quantum concept of the wave, the meaning that I am only proximally distinct from the sun becomes clear. I implicate the sun and the sun implicates me as a temporary and vital accumulation of its energy and light. Unities Schneider argues, are therefore proximal because they are

[141] Keller, C., (2015) p164
[142] Keller, C., (2015) p165
[143] Bohm, D., & Hiley, B J., (1993) p389
[144] Bohm, D., & Hiley, B J., (1993) p389
[145] Schneider, L., (2008) *Beyond Monotheism: A Theology of Multiplicity,* Routledge, Abingdon, Oxford, Ch.11.

temporary, and expand communally into unfinished totalities made up of ever-new connections thereby making possible and thus implicating yet new configurations and possibilities and becomings.[146]

Luce Irigaray the author of much contemporary French feminist commentary, suggests that this 'openness permits exchange, ensures movement, prevents saturation in possession and consumption.' As she remarks, each 'I' thus emerges as a nexus of exchanges, constituted by those exchanges rather than tolerating or enduring them. This deeply interactive relational quality of existence undercuts the coherence of the isolatable self.[147]

Bodies occur, they generate or express time and space, all the building blocks of matter constitute bodies as intervals of change. And because intervals of time make space and describe matter, incarnation is a revelation of divinity-in-flux. This is an ontology of 'is' of 'and'. Bodies exceed the 'is' in every occurrence because of their implication, expression and movement into and out of place and moment. Divine multiplicity in other words comes to body, to individuation, to being differently every time, in every instance of incarnation. Incarnation - divine becoming which is becoming flesh - is a material event of distinction that expresses time and space and in some sense '[makes] a difference.'[148] Becomings stretch and shape an event and so express space and time in and through relation to other bodies' gravitational attraction. It is this mysterious effect that all bodies no matter how big or small exert on one another. Divinity in the multiplicity of incarnation occurs with 'the freedom to come and go; to fold into the deep; to unroll a surface of explicit presence; to strain out of the womb into a homeless starry night, to weave gravitational complexities that we call communities or worlds. It is not a principle but an occurrence.'[149]

Fluidity, porosity and interconnection all characteristics of divine multiplicity, however are only part of the story. Divine multiplicity requires an attention to heterogeneity to otherness that is created in its unfolding articulation of change. The positive differences that occur in the world are affirmed by this elemental difference. Without attention to difference, to worlds of difference, bodies disappear, and any concept of divine multiplicity characterised by fluidity is liable to fall again into the trap of ignoring distinction in matter. In such unknowing, bodies become abstracted into classifications, types and identities. So only

[146] Schneider, L., (2008) Ch.11
[147] Irigaray, L., (1999) *Elemental Passions*, Collie, J., & Still, J., (trans) Routledge, New York, p63.
[148] Schneider, L., (2008) pp167-168
[149] Schneider, L., (2008) p167

through disappearance into types can bodies seem to appear.[150] Schneider asserts however, that divine multiplicity is all about the differences that incarnation makes.[151] Bodies thus accomplish difference from other bodies, from the world and even from themselves in their particularity.[152]

Conclusions

Jean Baudrillard argues as a human body ages, the change of youthful body into aged body into earth is not an exchange of equivalence. [153] The body that was young cannot take the place of the body that is now old. Everything is lost in bodies as they shift shape, especially the body-that-was. New worlds open as youth is outgrown, but the new age does not replace the lost youth. No thing can ever be fully exchanged for or cancel out another thing. Most subtle attempts to make the world meaningful in value terms, to endow it with meaning, come to grief on this insuperable obstacle.[154] Actual bodies are not finally reducible either to each other or to the generalities that we assign to them in our own becoming-related stories. Always exceeding the limits of language, incarnation is a becoming-different, a deferral of sameness. No one can be exchanged for another, both because it is not another, but also because every-one, everything has altered already every other.

Jacques Derrida observes that it is here that ethics finally fails. How can we assign value to the utterly unique and inexchangeable?

> [What] status must be assigned to this exemplarity of re-mark? How do we interpret the history of an example that allows the re-inscription of the structure of universal law upon the body of an irreplaceable singularity in order to render it thus remarkable?[155]

When ethics is some measure of 'right' and 'wrong' it falls apart in respect of bodies. There where right and wrong have no basis of exchange, what is possible however is decision and responsibility, but not any system of ethics. This is because of bodies. The impossibility of exchanging one body for another, one moment for another or even one world for another

[150] Schneider, L., (2008) p164
[151] Schneider, L., (2008) p167
[152] At the level of the particle.
[153] Baudrillard, J., (2001) *Impossible Exchange*, Turner, C., (trans), Verso, New York, p6.
[154] Baudrillard, J., (2001) p6
[155] Derrida, J., (1998) *Monolingualism of the Other Or, the Prosthesis of Origin*, Mensah, P., (trans), Stanford University Press, Stanford, p5.

means each is invaluable, and consequently inaccessible to systems of whatever sort, which of course includes ethical systems.[156] It is only when we forget the messiness of life which complexity brings in the passage of real, actual bodies, we can indulge in the kind of ethics that presumes systems of comparative value that can assign status and make exceptions in a life wholly implicated in the complicated world. Emmanuel Levinas argues ethics as the vulnerable face of the other which confounds any justification for any universal or objective claim that in any way reduces the other to a category of person or thing. To be other, to be distinct, itself inexchangeable, but the face must be real; it must be a body, and so gravitationally pull other bodies.[157]

Decisions do have to be made, but none is pure, static and equally none is ethical. Ontology and ethics come closer in a logic of multiplicity to stories which in their turn have seasons. They never conclude, and we never get the telling quite right - although sometimes we do for the time being. We have our moments and our seasons, so the story changes, we are changed by the story and the listener in the meantime has also changed, indeed so too has the world. Thus ethics becomes a 'minefield' a slippery concept in a complex multiverse.

Leaving aside all that has been said so far about the body, its gross and subtle characteristics; its place and interrelationship with the cosmos at the most profound quantum level; the metaphor that is the potential for the particle and wave to be the foundation for human spirit, belief, faith and hope in an ever becoming, constantly dynamic universe. The study now grounds the evidence presented on the meaning of the body to the implications of the processes of organ donation and transplantation for a wholistic interpretation of the body, from the viewpoint of informatics. Chapter 3 details the statistics of donation and transplantation, the legal position, methods of consent and the myriad related complexities that act as a backdrop to the present ethical frameworks developed in support of their findings.

[156] For me an *ethical system* implies a structured, static set of criteria to deal with similar issues, to be followed consistently in overcoming problems. I am advocating an approach to bioethics which takes into account the inexchangeability of the individual and the messiness of life as significant in creating greater flexibility and hence what value might mean to each person. However paradoxical my efforts, I do take Derrida's point.
[157] Levinas, E., (1990) *Difficult Freedom: Essays on Judaism*, Hand, S, (trans), John Hopkins University Press, Baltimore.

Chapter 3

The Facts and Figures so far. . .

Introduction

In contrast to the previous discussions, Chapter 3 sets out the current state within the medical specialism of organ donation and transplantation. It acts as a contrast to the alternative perspective of the body already proposed, and gives grounds for the argument that the lack of organs for transplantation dominates over long-term care for those involved in the transplantation process - donors, patients and relatives. In turn it underpins the case for a focus on patient narrative and caring as central to any future bioethical approach.

Key issues involving a broad range of professionals from bioethicists and policy-makers on the one hand to clinicians, patients and donors on the other are discussed. Included also are certain normative issues which are raised specifically to heighten awareness to the types of problem which those concerned encounter on a day-to-day basis. The chapter begins with a general comment on the research area. It then surveys a variety of textual material: some key statistics; types of donation; various modes of consent; legal requirements that govern the usage of human material; tissue banking; financial considerations and it concludes with transplant-tourism and organ trafficking.[158] Together these have considerable influence on the framing of consent and the resulting ethical decisions. In fact modes of consent and legal matters have a fundamental bearing on the various ethical models and tools as

[158] Further detail of transplant terminology and types of donation are outlined in the Appendices.

protocols to aid the medical profession in determining their options in increasingly complex medical matters in general.

The practice of donation and transplantation dates back before the Common Era - there are texts supporting cases in India and China where surgical procedures were performed. Although the evidence presented could well be apocryphal particularly in the case of the Chinese surgeon Pien Chi'ao, sources do quote and substantiate these dates.[159] These procedures were of course, totally unregulated. Regulation came into force in the United Kingdom (UK) through the Anatomy Act of 1832 that was passed in order to prevent the stealing of bodies for dissection. The infamous William Burke and William Hare - otherwise known as 'the body snatchers' committed a series of sixteen murders over a period of some ten months in 1828 in Edinburgh; the bodies from which they sold to Dr Robert Knox for dissection at his anatomy lectures.[160] In a move to prevent the recurrence of similar events, the Anatomy Act of 1832 was written into law and covered the disposal of bodies after death and the licensing of teachers in anatomy.[161]

Details of early transplantation procedures in the UK can be found in the history of transplantation outlined in the timeline in the Appendices. Whilst only progress in transplantation and organ donation are shown in the timeline for the UK, it should be noted that both the United States of America and the United Kingdom have been significant in the evolution of transplantation programmes and procedures. It must also be remembered however that Dr Christiaan Barnard pioneered the first heart transplant in 1967 in South Africa and since the early 1990s solid organ transplants have been performed successfully worldwide.

On closer examination of the timeline, evidence shows that overall regulation and indeed legislation appears to lag far behind biotechnical advances in the UK. There is clear evidence of considerable chaos in the UK's national health regulatory systems both historically and currently. This exacerbates the position with respect to policy-making and hence impacts

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[159] Pien Chi'ao was reputed to have performed double heart transplants on two men to achieve body balance. See: Woodford, P., (2004) Transplant Timeline. *National Review of Medicine*; **1:20**, Pien Chi'ao 500BCE. and Sara, S., & Parihar R S., (2007): Sushruta the first Plastic Surgeon in 600 BCE. *The Internet Journal of Plastic Surgery*. **4:2**

[160] Edinburgh was a leading European centre of anatomical study in the early 19th century in a time when the demand for cadavers led to a shortfall in legal supply. This shortage resulted in an increase in grave robbing by what were known as resurrection men. Scottish law at the time required that corpses for medical research should only come from those who had died in prison, suicide victims, or from foundlings or orphans. www.edinburgh-history/burke-hare accessed 21/09/2011.

[161] The Anatomy Act 1832 www.wellcomecollection.org /articles/trial-william-burke-1929 accessed 21/09/2011.

upon the difficulties faced by those who have to take extremely sensitive decisions in the medical setting of organ donation and transplantation. Interestingly in the USA, by contrast, updates to legislation and administration are considerably more regular, since litigation is at the forefront of their policy systems, especially those involving the full range of issues within the medical profession. The ramifications of the differences in legal requirements have significant influence on distribution of transplantation resources globally since legal obligations differ considerably between jurisdictions - a point that is covered in the section on governing legal principles in this chapter.[162]

The inclusion of a timeline historically positioning advances in transplantation gives a visual impression of the knowledge domain so that which follows can be put into a clearer context.[163] The fuller picture however includes legal, academic, commercial and media material as they each highlight and contribute toward the ethical frameworks that presently inform decision-making in the UK. Given accelerating advances in biotechnology at no time has the matter of appropriate ethical input been more important than it is today.

Informatics

There is a global shortage of organs for transplantation. Media attention in the UK continually seeks to raise awareness of this shortage by focusing on issues such as the increase in people paying for private procedures from organs obtained on the National Health Service (NHS) in order to 'jump' the NHS queue for transplantation; the inclusion of a mandated question in the UK driving licence application to register as a donor; the question of incentives for donors, and the explicit marketing of biotechnological advances.

The critical problem for the medical profession is highlighted by the fact that in March 2017 in the UK, statistics indicated that the ratio of people on waiting lists for organ transplantation to those who were registered as donors was 3:1.[164] For every person who receives a vital organ three patients will die whilst waiting on the transplant list. Whilst there has been a significant increase in donors over a number of years, the ratio in contrast has remained very similar. The global shortage of organs raises various ethical issues, not the least of which has resulted in the practices of organ trafficking and transplant tourism.

[162] See pp74-79 in this study.
[163] See the Timeline in the Appendices. Data collected from www.wellcomelibrary.org
[164] NHSBT Transplantation Activity Annual Report and Accounts for the UK as at April 2017, www.nhsbt.nhs.uk

Diverse initiatives have been legalised as a result of recommendations from ethical organisations in the UK including the Nuffield Council on Bioethics (Nuffield), the British Medical Association (BMA), the Organ Donation Taskforce (ODT) now the remit of local Care Commissioning Groups (CCGs) set up in 2013, and the National Institute for Health and Care Excellence (NICE). Their specific remit has been to discuss and research modes of donation, donor incentives and the role of altruism in the issue of consent.[165] They are equally tasked with ethical measures to aid in increasing organ supply in order to lessen the problems of global trafficking and tourism. Such issues together with ethical concerns such as the legal position with respect to ownership of body parts will be considered in greater depth in Chapter 4.

Donation

Organ donors may be 'living' or 'brain dead' additionally organs may be recovered from donors who are 'cardiac dead' often termed as cadaveric donors whose breathing and heartbeat has ceased. Tissue may be recovered from donors up to 24 hours past the cessation of heartbeat, however in contrast to organs, most tissues with the exception of corneas, can be stored in tissue banks for up to five years.[166] Thus tissue transplants are much more common than solid organ transplants. Until relatively recently, organ donors were routinely relatives of the recipient. As a result of medical advances in immunology, and providing tissue typing is consistent between the donor and the individual receiving the organ, it is now possible to donate to unrelated recipients.

Some statistics of live and deceased donation

The period 2016-2017 shows a marked increase in deceased donors in the UK:

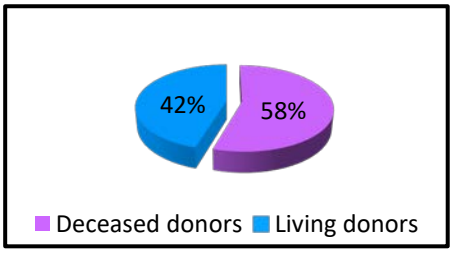

Figure 1: Percentage of living and deceased donors in the UK 1st April 2016 to 31st March 2017

[165] See the BMA Report 2012: Building on Progress: Where next for organ donation policy in the UK, www.bma.org.uk The Organ Donation Taskforce Report 2013: Taking Organ Transplantation to 2020, www.nhsbt.nhs.uk/to2020 and the Nuffield Council on Bioethics Report 2011: Human bodies: donation for medicine and research, nuffieldbioethics.org/publications

[166] Nuffield Council on Bioethics Reports 2011, nuffieldbioethics.org/publications

The decade between 2005 and 2015 saw major changes taking place in how organ donation and transplantation is delivered. Those changes have continued; donors are older, more obese, and less likely to have suffered a trauma-related death, all of which have adverse effects on transplant outcomes.

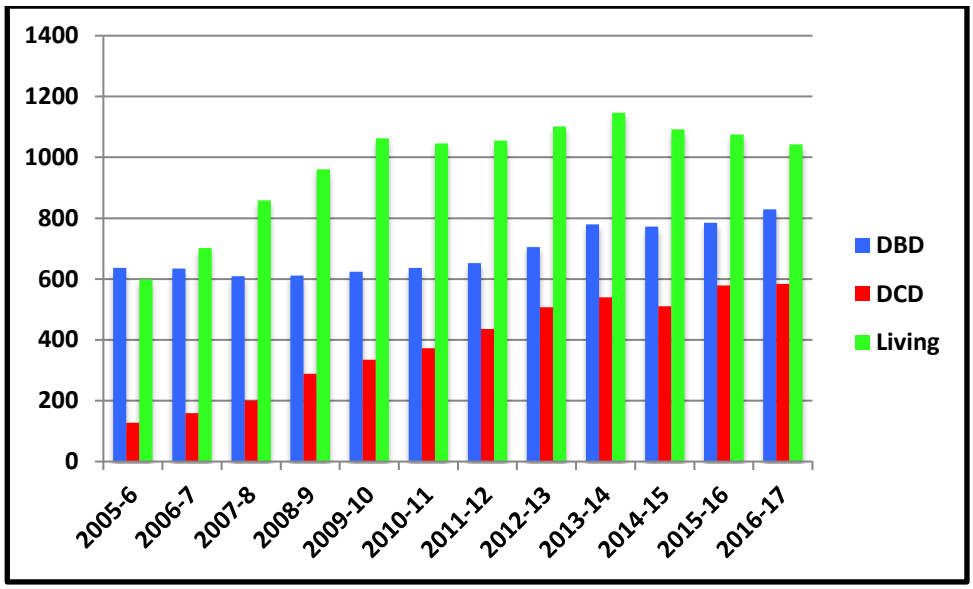

Figure 2: Numbers of deceased and living donors in the UK, 1st April 2005 to 31st March 2017

According to the 2017 statistics the number of deceased organ donors has increased from the previous year and overall deceased donation has risen since 2005 by some 50%. There has been an overall increase in donation after brain death (DBD) as well as circulatory death (DCD), in fact the number of deceased donors rose to the highest number ever recorded in the UK.[167] However, statistics show a small but steady decline in living donation over the period 2014-2017 which has clearly had an impact on overall donation rates, see **Figure 2**. The number of transplants in adults in 2016-2017 was 3169 for kidneys, 213 for pancreas islets, 966 for liver, 200 for heart only and 176 for lung only, see **Figure 3**.[168] Kidney transplantation remains the most prevalent and easily the most successful of procedures according to NHSBT Transplant Activity Reports.

[167] **Figure 2**: Numbers of deceased donors in the UK April 2005 to March 2015, from: Johnson, R J., Bradbury, L L., Martin, K., & Neuberger, J., (2014) Organ Donation and Transplantation in the UK - The Last Decade: A Report from the UK National Transplant Registry, in *Transplantation*: **97:1S:S1-S27** together with 2014-2017 figures from the NHSBT Transplant Activity Report.

[168] NHSBT Transplant Activity Report, figures for the UK as at April 2016, www.nhsbt.nhs.uk

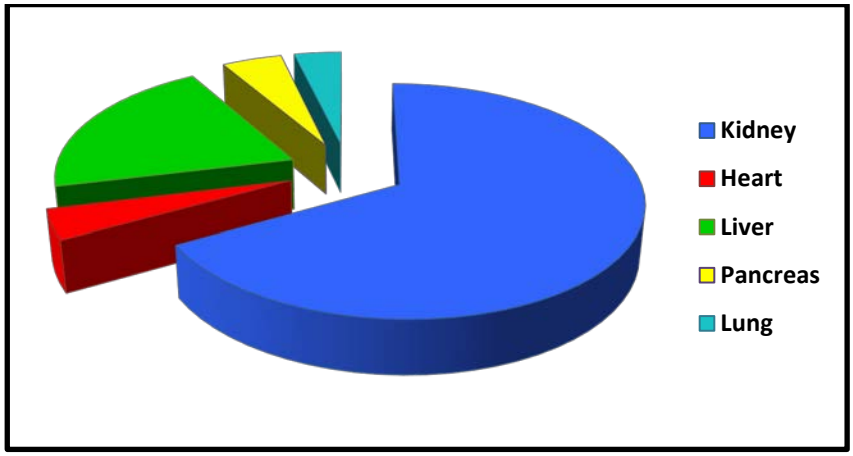

Figure 3: The ratio of transplants by type of organ 1st April 2016 to 31st March 2017

The total number of kidney transplants increased by 2% in 2016-2017, the total number of cardiothoracic transplants fell by 2%, liver transplants increased by 6% but pancreas transplants fell by 3%.[169] Despite these figures the number of patients on the transplant waiting list has varied over the last ten years, but 457 patients died in this last period whilst waiting for a transplant, and the average waiting time for a kidney for example is around 880 days. It would appear that despite all measures to encourage donation and thereby increase the number of organs there will be a possible shortfall to fulfil NHSBT's target for 2020.[170]

Deceased donors

Deceased donation is problematic. Deceased donors are those who have been declared 'brain-dead' and are neurologically tested as such, or have died following cardiac arrest. In cases of brain death the donor has received trauma to that part of the brain that controls heartbeat and breathing - a circumstance that is frequently caused by serious accident. Such a functional definition continues to raise concerns relating to what constitutes brain death and its consequent identification. For many this issue remains unresolved. According to Alistair Campbell:

> The main disagreement is between those who advocate *whole brain death*, which requires that both the higher (cortical) and lower (brainstem) parts of the brain are ceasing to function and those who advocate *higher brain death* (cessation of function of the cerebral hemispheres resulting in irreversible loss of consciousness, and the abilities to think, feel and relate to others.)[171]

[169] During this period multiple transplants such as heart/lung were carried out however figures are not presented here but are available on the NHSBT website. See note below.
[170] NHSBT 2016-2017 Transplant Activity Annual Report and Accounts, www.nhsbt.nhs.uk
[171] Campbell, A V., (2009) *The Body in Bioethics*, Routledge-Cavendish, Abingdon, Oxford, p111.

By contrast, from a religious perspective, the Catholic Church advocates a requirement for moral certainty of death rather than its functional certainty:

> [*T*]*he death of the person* is a single event, consisting in the total disintegration of that unitary and integrated whole that is the personal self. It results from the separation of the life-principle (or soul) from the corporal reality of the person. The death of the person, understood in this primary sense, is an event which *no scientific technique or empirical method can identify directly.* Yet human experience shows that once death occurs *certain biological signs inevitably follow*...the traditional cardio-respiratory signs...[or] the complete and irreversible cessation of all brain activity.[172]

In agreement with the sentiment of Pope John Paul II, Robert Veatch claims that the definitions of brain death or indeed cardiac death 'obscure the fact that we are searching for the meaning of death of the person as a whole' rather than a specific level or locus.[173] This raises a further point that those determining or defining the death of a patient should not be physicians with an interest in acquiring organs. For example, William May believes it important that there is a separation between the question of defining death and the use of organs for transplant in order to protect the dignity of the dying person.[174]

Evidence has shown that the problem of defining death is of concern. It introduces ethical dilemmas that appear to be difficult to resolve. Such ethical complexity is compounded in the matter of ventilation that aids in maintaining the viability of organs for transplant by keeping the body ostensibly 'alive' whilst in reality death has already occurred.

Living donors

Living donors donate renewable tissues such as an organ or part of an organ, in which the remaining organ can take on the physiological workload, as in the case of single kidney donation. In partial donation such as liver lobe, pancreatic islets or small bowel cases it is reported that regeneration can and does take place. Whilst the risk of death from living donation is fairly rare, living donors are quite often listed for kidney transplantation themselves at some later point for instance.[175] Numbers of organs for transplantation are

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[172] John Paul II (2000) Eighteenth International Congress of the Transplantation Society, Libreria Editrice Vaticana, Vatican Press, Italy, para 4.
[173] Veatch, R M., (1976) *Death, Dying and the Biological Revolution: Our Last Quest for Responsibility,* Yale University Press, New Haven, USA, pp24-25.
[174] May, W E., (2008) *Catholic Bioethics and the Gift of Human Life*, Second Edition, Our Sunday Visitor Publishing, Huntington, Indiana, p316.
[175] Price, D., (2009) *Human Tissue in Transplantation and Research, A Model Legal and Ethical Donation Framework*, Cambridge University Press, Cambridge, p199.

increased by the practice of domino transplanting and paired and pooled donation. Procedures which are on the increase globally.[176]

Initiatives to increase the number of organs for transplantation include, specific regenerative medicine using patients' own cells in the form of healthy cells extracted from their failing organs or alternatively from stem cells which can be used in isografting.[177] In 2016 an investigation into the growth of human organs in livestock, specifically pigs and sheep by the government's animal research advisers was undertaken. The procedure involves genetically removing an organ in the animal embryo then injecting human stem cells which it is hoped will replace the missing organ before putting the embryo in the womb of a female pig or sheep. About 20 livestock were impregnated at universities in the United States in the year 2015-2016 and a further 36 or so pregnancies are thought to have taken place in other countries.[178]

Consent discussions and debates

Before any surgical intervention of whatever kind, consent must be sought from those involved in the procedures - the medical professional who administers the forms and the patient, or by a relative in circumstances where this is inappropriate because of the patient's mental capacity, age, or they have died without agreeing to donate. Donors may be living or deceased as discussed. In the case of living organ donation, consent is required from donors who are perfectly healthy but through choice have offered an organ or organs as a perceived act of charity to an individual who is in need and who otherwise might die. The fact of agreeing to donate brings with it a diverse range of complex issues surrounding the framing of that consent. It is therefore important to understand how these various modes of donation function, since highlighting the difficulties involved and the effectiveness and limitations of each of the methods enables a greater understanding of the ethical issues.

Methods of consent to donation

Consent is of crucial ethical concern in contemporary debates relating to the donation of human material. The subject of donation has historically perplexed the many professional

[176] See Appendices for definitions of transplantation types.
[177] See Appendices.
[178] The Times 11th January 2016 article: Human organs for transplant grown inside sheep and pigs, www.thetimes.co.uk/article/human-organs-for-transplant-grown-inside-sheep-and-pigs

organisations involved in how consent should be structured. In this context Professor Margaret Brazier comments that '[C]onsent is such a simple word and is the more beguiling and elusive for that.'[179] And David Price suggests that the 'perceived' or 'actual failure' to obtain proper consent has been central to many controversies in transplantation and research spheres.[180] The most well-known example is the post-mortem and tissue retention scandals that occurred in the early part of the twenty-first century in the UK.[181] Generating sufficient body parts for those in need and the rights of individuals or their families to control the use of such materials continues to be problematic as the NHSBT 2017 (National Health Service Blood and Transplant) Transplant Activity Report points out. Despite an increase of 50% in organ donation overall, although the number of living donors has fallen since 2014, there are almost seven thousand people in the UK in need of an organ transplant.[182]

Different notions of consent prevail in official policies and widely varying laws and practices exist around the world. Since the allocation of organs relies solely on a list-based system, appropriate mechanisms for consent are fundamental. In the UK, the two key systems that have been developed and agreed by the various advisory and ethically based organisations are termed **opting-in** and **opting-out:**[183]

- The scheme for **opting-in** is recognised as appropriate consent, permitting tissue and organs to be posthumously removed for transplantation, through the carrying of a donor card or by permission made explicit in the conditions laid out in a will.
- The scheme for **opting out** is considerably more problematic. Otherwise known as presumed consent, the scheme permits tissue and organs to be posthumously removed for transplantation unless an individual has previously raised an objection, in which case consent is withdrawn.

Opting-in would appear to be relatively straightforward in theory, in practice however, the situation is somewhat different. Many sources reveal that unless relatives are advised of the deceased's intentions from their will prior to death, or indeed are aware that they carried a donor card, or otherwise have discussed donation, the deceased's wishes may not be carried

[179] Brazier, M., (2003) Organ retention and return: Problems of consent, *J Med Ethics*: **29:1**:**30-33**
[180] Price, D., (2009) p2
[181] Evidenced by the Alder Hey inquiry where the organs of 3,500 children were retained without consent, and the Bristol Royal Infirmary Interim Report (2001) reporting that the hearts of 170 dead children had been retained without consent.
[182] NHSBT (2017) Transplant Activity Report, www.nhsbt.nhs.uk
[183] Particularly in reports from the WHO, Nuffield Council on Bioethics, Organ Donation Taskforce, NHSBT and a multiplicity of media articles.

through. In this case the relatives are able to override consent for whatever reason. With time being of essence in organ excision and thence transplantation, the likelihood is that relatives will not be in possession of important information to make their decision in order that timely surgical procedures can be performed. This potential loophole in the system is in part responsible for the problems of organ scarcity. The question of tightening up this anomaly therefore is a very live topic in frequent debates.

According to NHSBT news in January 2016, the organisation responsible for the NHS Donor Register and for matching and allocating donor organs is investigating whether there are further steps it could take when approaching families to ensure more potential deceased donors' wishes are honoured by their relatives - around five hundred families in the UK said no to organ donation during in 2016 and the Activity Report for 2017 showed a similar figure.[184] The 2017 report includes statistics showing prime reasons for families not supporting donation that cover part of the 2016 initiative.[185] Within that initiative a number of ideas were proposed to offset refusal including: providing families with a leaflet explaining that consent rests with the person who has died and not the family left behind; asking families to assess any risk to donation - such as an unforeseen disease resulting from donors having travelled overseas and fallen ill. And finally, asking families to sign a document confirming their reasons for overriding a relative's decision with the aim ultimately that the family will honour the relative's original decision. Objections raised to a number of these proposals involve contravention of the ruling of non-coercion.[186]

As a further measure to increase organ supply, the BMA in their 2012 report pushed for the procedure of elective ventilation.[187] Ventilation is the procedure by which organs are preserved in a suitable state for transplantation by mechanically keeping the patient 'alive.' This process has incurred concern from some physicians who question whether frustration over the static number of DBD donors has resulted in 'an intervention that could jeopardise professional and public confidence in all forms of donation' and arguing that such practices 'are at the very edge of acceptability.'[188]

[184] NHSBT News 15th January 2016 article: Families saying no to donation results in missed transplant opportunities for UK patients, www.nhsbt.nhs.uk
[185] See NHSBT Activity Report 1st April to 31st March 2017 Table 13.10, www.nhsbt.nhs.uk
[186] Unless there is to be some waiver of the consent that relatives habitually give.
[187] BMA Report (2012) Building on Progress: Where next for organ donation policy in the UK?
[188] BMA Report (2012) p38

In matters of consent, there is a distinction to be made between living and deceased donors. For living donors the systems and laws currently in place are intended to ensure protection of both autonomy and respect for bodily integrity. Little dispute exists about removal of organs from living donors either for transplantation or research since it is the interests and wishes of the donor that are the prime determinant. This too is reflected in global policies. Under these circumstances the rights of relatives and close friends are of no real relevance in the decision-making process, although exceptions may be made in respect of parental responsibility and for those with diminished capacity to make those decisions. Where an individual interest is infringed however, this constitutes a 'legal or moral harm' and is subject to the law. As Lori Andrews and Dorothy Nelkin state:

> A person's control over what is done to his or her body, or its parts, is important to his or her psychological development. It is a way of establishing personal identity and conveying value to others.[189]

By contrast, the issue of what interests exist with respect to the dead, is contentious and the subject of diverse opinion. This diversity shows itself in various attitudes towards conscription/presumed consent, mandated choice, directed donation and informed consent. It would appear that for deceased donation existing policies (such as obtaining consent from relatives, where none has been explicitly given by the deceased in a will for example) places a higher value on respecting the relatives' autonomy rather than on maximising the recovery of organs. John Harris for instance argues for a form of conscription understood as presumed consent since:

> The necessity of obtaining consent for cadaver transplants costs many hundreds of lives each year…Where there is no kidney donor card, for example, the necessity to find next-of-kin and find them in any condition to entertain the question of transplants from their nearest and dearest means that many potential donor organs are lost.[190]

The system of opting-out is legal in some countries including Spain, Belgium and Italy, where it has reportedly been very successful. However it has attracted criticism from many ethical bodies for its perceived lack of concern for the autonomy of the individual.[191] Whilst Wales agreed to a soft form of presumed consent in 2013, presumed consent had been excluded

[189] Andrews, L., & Nelkin, D, (2001), Body Bazaar in: *The Market for Human Tissue in the Biotechnology Age,* Crown Publishers, New York, p13.
[190] Harris, J., (1985) *The Value of Life: An Introduction to Medical Ethics*, Routledge & Kegan Paul, London, p119.
[191] Nuffield Council on Bioethics (2011) Human Bodies: donation for medicine and research, Nuffield Press, London.

from legal sanction in the whole of the UK for numerous years.[192] However, it has been suggested that the British government will be taking a vote imminently to write opting-out into law.[193]

Those who advance presumed consent advocate certain additional advantages such as cost, efficiency, avoidance of delays and the relief from stress for healthcare staff who would otherwise have to request donation, and for families who currently have to make such decisions at an extremely difficult time. Indeed Aaron Spital and James Taylor suggest '...even if we are mistaken in our sceptical view of the concept of posthumous harm, this would not change our belief that routine removal of usable cadaveric organs is the way to go.'[194] The views expressed by Harris and Spital and Taylor accord particularly with a utilitarian perspective that seems especially prevalent in transplantation medicine.

On the other hand, Albert Jonsen maintains that 'consent is ethically important because it manifests and protects the moral autonomy of persons...it is a barrier to exploitation and harm. These purposes are no longer relevant to the cadaver, which has no autonomy and cannot be harmed.'[195] The argument would follow therefore that the deceased has no interests at all in their organs after their demise and consequently cannot be harmed by whatever decisions are made concerning their removal. In fact in any event there is a view that whatever interests do exist they are outweighed by the immediate interests of those requiring such materials for their welfare. Sells states unequivocally that the shortage of organs will not be alleviated until opting out, otherwise known as presumed consent, is legalised and thereby numerous lives will be saved.[196]

As a more prescriptive initiative, mandated choice is yet a further system for eliciting consent. It is exemplified in the August 2011 driving licence agency's scheme to mandate the previous optional question of donation on the licence application form, before approval for both new and renewal applications. However this approach targets especially the nation's youth who are the ideal donor category. Naturally these are young people whose organs are ostensibly free from health issues associated with advanced age, but within this

[192] The form of presumed consent is termed 'soft presumed consent' which still gives the opportunity for relatives to withdraw that consent at the time.
[193] The Daily Mirror Wednesday 12th July 2017: MPs to vote on organ donation opt-out system as hope grows for sick patients.
[194] Spital, A., & Taylor, J S., (2007) Routine recovery of cadaveric organs for transplantation: Consistent, fair and life-saving, *Clinical Journal of the American Society of Nephrology*: **2**
[195] Jonsen, A., (1998) Transplantation of fetal tissue: An ethicist's viewpoint. *Clinical* Research: **36:3:215-219**
[196] Sells, R A., (1990) *Transplant Proceedings*: **22:931-932**

age group, the incidence of deaths from automobile, motorcycle, and bicycle accidents is high. The license application form requires answers to three questions:

- Yes I would like to register.
- I do not wish to answer this question now.
- I am already registered on the NHS Organ Donor Register.[197]

Of importance is the omission of the option to refuse to donate, which as Nuffield points out is non-trivial, since it sends out an inappropriate message by the apparent neglect of autonomous choice.

Directed donation is yet a further option for donors who consent only to organs being given to named relatives or friends or indeed to a specific race or gender. It should be noted that ethnic minority groups are the least like to either donate or receive an organ for instance. This is a departure from the supposed requirement for anonymous, altruistic donation. Directed donation does raise certain ethical concerns over the communitarian ideals of solidarity - that an organ is given freely within the spirit of 'we are all in this together.'[198] It also calls into question the notion of property rights in terms of an individual's autonomous choice to determine appropriate use of their donated bodily material according to their expressed instruction.[199]

Finally there is the vital question of the framing of consent. It is paramount that the consent given should result from a properly informed choice; that is the maximum intelligible information is offered for that choice to be made. With advancing biotechnical options and the differing legal possibilities such as the use of certain organs of the body or all internal organs for donation or research or tissue banking, this has become increasingly problematic. Neil Manson and Onora O'Neill consider consent from an alternative perspective.[200] In criticising standard methods which have traditionally focused on improving procedures, or making consent requirements more user-friendly, their approach involves finding ways of cutting through the obligations, legal rights and protections that are in general well understood and articulated. Informed consent in a climate of advanced biotechnology they state 'cannot and should not, aim to be fully specific, or fully explicit' and the aim should be for a communicative transaction between doctor and patient or donor - the equivalent to

[197] See the Driving and Vehicle Licencing Agency at https://dvlalicenceservices.co.uk/apply
[198] Nuffield Council on Bioethics (2011) p154
[199] Price, D., (2009) pp271-273
[200] Manson, N C., & O'Neill, O., (2007) *Rethinking Informed Consent in Bioethics*, Cambridge University Press, Cambridge, pp vii-xi.

trust perhaps. The emphasis is then shifted to the process of understanding the underlying communicative event rather than the consent itself. In proposing this alternative move they support John Searle's linguistic form - the Speech Act.[201] The Speech Act illuminates the meaning and intention behind the interaction, so that both sides have the opportunity to negotiate the linguistic sense of the transaction. Ultimately this opens up the potential for a clearer more perspicuous understanding. The possibility of paternalism is lessened, and greater value and respect is given to the patient or donor for their part in the communicative act - a point that will be considered from various ethical positions throughout this study.

The use of human material raises deep concerns about the relationship between bodies and personal identity and generates fundamental questions about who we are and what sort of society we wish to live in.[202] Questions remain over wider ethical perspectives such as the potential for profit from human body parts and the increasing value and utility of human resources. Evidence shows that deep divisions exist between those commentators adhering to mechanistic, utilitarian points of view and those whose attention focuses on valuing the body in non-materialist terms. In this vein, Price acknowledges that valuing the body in such a mechanistic manner highlights the vulnerability of our bodies and underpins the need for donor and indeed community interest to be properly protected through the rule of law.[203]

Legislation affecting organ donation and transplantation

Many Acts and laws exist globally in respect of organ donation and transplantation each of which reflects the norms and values of their respective cultures. The focus of this section will be to discuss the major legal requirements as they affect donation and transplantation throughout the UK. Across most of the UK, there is a comprehensive framework governing the use of human material for research, transplantation and other medical purposes. Concerns that need to be addressed however, relate to the safety and quality of human material, potential limitations on use and commerciality, and the suitability of personnel and premises involved in the handling of bodily material. In general legislation for the dead is more extensive than for the living. The Human Tissue Act of 1961 made provision for the use of parts of bodies of the deceased for therapeutic purposes, medical education and research, and additionally for 'respect to the circumstances in which post-mortem examinations may

[201] Searle, J R., (1965) What Is a Speech Act? in *The Philosophy of Language*, 2nd edition, Martinich, A P., (1990) (ed.), Oxford University Press, Oxford, pp115-125.
[202] Price, D., (2009), pp271-273
[203] Price, D., (2009), pp271-273

be carried out; and to permit the cremation of bodies removed for anatomical examination.'[204]

More specifically the Human Organ Transplants Act of 1989 underpinned the necessity for 'genetically related' persons as donors in order to eradicate trading in human organs for transplantation. Laws however employ sub-categories of materials, or distinctions for various ends. The 1989 Act distinguished 'organs' from other human materials, whereas the 2004 legislation now includes human material within its remit, but differentiates between organs and other human materials for licensing and other purposes. Bronwyn Parry states that the 1961 Act was revised in 2004 in order to respond to concerns raised by events at the Bristol Royal Infirmary and the Royal Liverpool Children's Hospital (Alder Hey) where organs had been stored and used without proper consent.[205] The report from a census published by the Chief Medical Officer for England in 2000 and the Isaacs Report published in 2003 revealed that the practice of retaining, storing and using organs and tissue taken from adults and children without proper consent had become relatively commonplace in the period from 1970 to 1995.[206] Whilst there is continuing concern over organ and tissue retention, the UK Human Tissue Act 2004 for instance does not apply consent to the removal of tissue and retention from the living, such issues are typically governed by the general law.[207]

The Human Tissue (Scotland) Act 2006 on the other hand distinguishes between organs and other materials for the purposes of retention of material removed post-mortem. The distinction between organs and tissues is intended to reflect the different emotional significance they allegedly have in this context.[208] In comparison however, the USA's Uniform Anatomical Gift Act 2006 only refers to allowing material from the deceased and describes 'an anatomical gift' as 'a donation of all or part of a human body' and defines a part of a human body as meaning an 'organ, an eye or a tissue of a human being.'[209]
The Human Tissue Act 2004 has been criticised for having too broad a remit and the adoption of a blanket approach to human material - in this regard, Parry states it was 'wholly

[204] Human Tissue Act (1961), HMSO, London, www.legislation.gov.uk
[205] Parry, B., (2005) The New Human Tissue Bill: Categorization and Definitional Issues and their Implications in *Genomics, Society and Policy*: **1:1**
[206] See Donaldson, L., (2001) Report of a census of organs and tissues retained by pathology services in England conducted in 2000, Government Stationery Office, London, www.webarchive.nationalarchives.gov.uk and Metters, J., (2003) The investigation of events that followed the death of Cyril Mark Isaacs, in the *Isaacs Report*, Government Stationery Office, London.
[207] The 2004 Act in the UK and the 2006 Act in Scotland do however contain edicts relating to both the removal and use of materials taken from living persons under the satisfaction of certain conditions that include an absence of reward given or to be given. See www.legislation.gov.uk
[208] Human Tissue (Scotland) Act 2006. Human Tissue Authority, Scotland, www.legislation.gov.uk
[209] Uniform Anatomical Gift Act 2006, Part 1. USA.

unnuanced' with a failure to reflect the 'mischief' that the legislation was designed to remedy as in the case of the retention of materials, for example. She goes on to state that the first draft of the Bill was 'underwritten by a presumption that individuals have an undifferentiated relationship to their extracted body parts.'[210] In a joint paper with Gere on tissue banking and in particular in the case of the Alder Hey scandal, Parry and Gere highlight the 'fracture in perceptions' of what matters and what does not in terms of the use made of human materials:

> So it seems that, on the one hand, for many of the parents whose children's organs had been retained at Alder Hey, tissue blocks and slides were unambiguously parts of the body, corporeal entities endowed with all the spiritual and emotional significance carried by the human remains of beloved family members. For most members of the medical establishment, on the other hand, "blocks and slides constitute a medical record", something to be filed with case notes and temperature charts.[211]

On this very issue Cathy Gere and Bronwyn Parry assert that we should not ignore the connection between human materials and their 'personal' origin. Whilst subsequent revisions continue to be written for the 2004 Act, the latest being in 2017, the basic tenor of the Act however remains the same, despite biotechnical progress having substantially re-ordered the way in which body parts are treated medically in the twenty-first century.
In addition to domestic and European law, there are relevant international conventions and guidelines that may influence UK policy on the donation and use of human bodily material:

- The European Union Organ Directive 2010/45/EU concerns 'standards of quality and safety of human organs intended for transplantation' implemented into law in 2012.

- The World Health Organization (WHO) first issued *Guiding Principles* on human organ transplantation in 1991. A revised and expanded version of these principles, embracing both organs and tissue, was endorsed in May 2010. The guidelines cover issues such as the global shortage of human materials - particularly organs for transplantation; the growing phenomenon of 'transplant tourism' partly caused by that shortage; quality, safety and efficacy issues related to transplantation procedures; traceability and accountability of human materials crossing borders.

[210] Parry, B., (2005) *Genomics, Society and Policy*: **1:1**
[211] Gere, C., & Parry, B., (2006) The flesh made word: Banking the body in the age of information, *Biosocieties*: **1:1:41-54**

- *The Declaration of Helsinki* was originally agreed in 1964 but is regularly revised - the latest being a significant revision in 2013. It covers research involved with humans and though it is not binding in English law it is considered a benchmark against which current UK projects are measured. Its principles include: the need for consent for all competent participants in research; the rights of subjects to withdraw from research; human experimentation to be used as a last resort where other forms of research involving non-humans are not possible and finally, a need for the balance of risk to the subjects involved and the benefits accrued by the research.[212]

- *The Declaration of Istanbul on Organ Trafficking and Transplant Tourism* was formulated in 2008. At that time The Declaration stated that 'organ trafficking and transplant tourism violate the principles of equity, justice and respect for human dignity and should be prohibited'. It demanded action to prevent the purchase and sale of human organs, along with activities such as advertising, medical screening and transport mechanisms. Regular policy documents continue to be written covering trafficking and related issues.[213]

One of the major worries pointed out by both legal and advisory bodies is the matter of transplant tourism. With the increasing flow of both organs and recipients across jurisdictions the potential for legal anomalies to occur increases exponentially in terms of quality of organs and procedures, quantity and permissible rulings - which includes money changing hands for surgery. Whilst diverse legal sanctions are in place, concern has been expressed that there is an increase in illegal movement of both organs and patients.[214]
I argue that far from merely highlighting that this global problem exists and in acknowledgement of the universal shortage of organs as already stated, it raises the question of some form of universal legal standardisation. Or alternatively some form of agreement in order to address the shortage, allow for cross-border procedures and thereby potentially undermine the dangerous trafficking problems that continue to exist.

Of significance for the United Kingdom, there are several further advisory bodies whose input has important influence on decisions taken by the various legal bodies, two of the most

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[212] Herring, J., (2012) *Medical Law and Ethics*, 4th edition, Oxford University Press, Oxford, p600.
[213] The declaration was supported by the Transplantation society, the World Health Organisation and the International Society of Nephrology. It calls for surgeons participating in such activities to be stripped of their medical qualifications: Price, D., (2009) p18. Further up-to-date documents and discussions can be found at the Declaration of Istanbul website www.declarationofistanbul.org/resources/policy-documents Papers as recent as October2017 call for international co-operation in the prevention of organ trafficking and organ removal.
[214] Price, D., (2009) pp16-19

active are the Nuffield Council on Bioethics and the National Institute for Health and Care Excellence (NICE). Nuffield is an ethics advisory body whose remit is to cover issues across the range of medical science. In the case of donation and transplantation it has produced two reports. The 1995 report examines such issues as the urgent need to consider, clarify and where necessary, strengthen the ethical and legal framework within which the clinical and research uses of human tissue take place. The uncertainty at the time risked impeding legitimate uses or even encouraging illegitimate uses of tissue; the patenting of surgical procedures and the ethical issues related directly to the core of respect for human beings, namely that they and their bodies should not be injured and that nothing should be done to them without their consent.[215]

The remit for Nuffield's research and subsequent 2011 report included: identification and definition of ethical questions raised by recent advances in biological and medical science; promotion of public understanding; limits on the promotion of donation including the role of payment and other forms of remuneration; the role of consent; and the role of the state as 'steward' in matters of general health. The working group also developed a framework based on altruism and the concept of payment as a tool to aid in future decision-making for organ donation.[216]

NICE, provides guidance on clinical integrity and in the case of organ procurement end-of-life care to potential donors, to the sensitive issue of consent and to the appropriate way in which relatives are approached.[217] NICE also works closely with the British Transplantation Society who also provide guidance to the medical profession from transplant co-ordinators to clinicians.[218]

The British Medical Association (BMA) that acts especially in the role of trade union for the medical profession also has an ethical influence on organ donation, though less in the interest of the patient and more with respect to donation and transplantation in general. The organisation acts as a voice representing the views of the profession.

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[215] Nuffield Council on Bioethics, (1995) Report: Human tissue: ethical and legal issues, Nuffield Council, London, www.nuffieldbioethics.org/publications

[216] Nuffield Council on Bioethics, (2011) Report: Human bodies: donation for medicine and research, Nuffield Council, London, www.nuffieldbioethics.org/publications

[217] Parry, B., (2005) *Genomics, Society and Policy*: **1:1**:**74-85**

[217] See NICE www.nice.org.uk/guidance

[218] See British Transplant Society www.bts.org.uk

When it was set up in 2006 the Organ Donation Taskforce (ODT) was an influential governmental organisation established to look into various initiatives to increase organ donation rates, such as advertising campaigns, media coverage in terms of television, newspapers reports and articles, the input of regulatory bodies and methods of consent.[219] Subsequently a nudge unit was established to concentrate on the task of increasing donation rates including coverage of this issue across all public media. The ODT was taken over by the NHS Commissioning Board in 2013 with a broader remit for patient care across all sections of medical treatment. The Commissioning Group published its planning guidelines *Everyone Counts* in that same year to all clinical commissioning groups (CCGs), covering targets, financial matters and improvements in customer healthcare.[220]

In order to implement the law in both the EU and the UK, regulatory bodies need to be in place. To this end the Human Tissue Authority (HTA) was established by the Human Tissue Act 2004 to undertake the regulatory roles set out in the legislation. However, this aspect of the UK regulatory landscape is in a state of flux, since the Department of Health announcement in July 2010 that the HTA would be abolished by 2015.[221] The Department of Health stated that the regulatory framework itself would not change, but rather that 'the functions of the HTA will be transferred to other organisations to achieve greater synergies where appropriate.'[222] There is however uncertainty as to how these regulatory bodies will absorb the remit of the HTA or indeed given the rate of change within the NHS, whether the HTA will be abolished at all.[223]

In fact the Organ Donation Taskforce recommended in their 2008 Report that one overriding body be established in the UK to advise the medical profession on ethical matters, especially in respect of ethical dilemmas and hence challenging decision-making.[224] Despite these supposed advances, Price expressed deep concerns around consent and policy development:

[219] Organ Donation Taskforce, (2008) Report: *Organs for Transplants*, Department of Health, London.
[220] NHS Commissioning Board, *Everyone Counts*, see: www.england.nhs.uk/2012/12/everyonecounts and www.gmcvo.org.uk/nhs-commissioning-board-website
[221] The Nuffield Council on Bioethics (2011) Report: Human bodies: donation for medicine and research, www.nuffieldbioethics.org/publications
[222] The Nuffield Council on Bioethics (2011) Ch.2.
[223] In 2017 the HTA is still very much in existence.
[224] Organ Donation Taskforce, (2008) Report: Organs for Transplants, Department of Health, London, Recommendation: 3.

> ...clear policy decisions need to be made with respect to the nature of the consent framework to be adopted and the infrastructural framework needed to be provided. At the present the role of relatives is not clearly articulated or illuminated as regards deceased donation in most explicit consent systems, creating a lack of clarity and a muddle at the heart of the process.[225]

Conclusions

Price's comment brings into sharp focus the continuing problems with appropriate consent frameworks. Equally he highlights the ever-present difficulties with the position of the relatives who are caught in a network of discussions and decisions at a very sensitive time. Policy rests on outcomes from these issues, which are at the very forefront of both global and UK debate.

It is a fitting time at this point to examine the key ethical sources which have led to the current position with respect to organ donation and transplantation, and to suggest that however important their input has been thus far, there may well be other equally significant knowledge domains to draw from to broaden the debate, and to offer an alternative perspective on what appears to be a somewhat intransigent position with respect to matters of consent and the consequent increase in organ supply. Discussion of these sources now continues in Chapter 4.

[225] Price, D., (2009) pp282-283

Chapter 4

Critical Analysis of Key Ethical Discussions and Debates

Introduction

The aim of this chapter is to put forward a critical analysis of those sources informing past as well as current bioethical debates on the subject of organ donation and transplantation and to deepen the discussions outlined in Chapter 3. The intention is to highlight both the strengths and weaknesses of the significant ethical issues arising in order to add force to a proposed alternative approach to the main bioethical frameworks that currently operate in the UK.

The giving and receiving of an organ are both complex and complicated events and since they involve major surgical intervention into the body, remain ethically challenging issues for those effecting and those who are affected by the processes. Matters of consent; doctor-patient relationships; the importance of gift-giving and altruism; payment and the apparent commodification of the body; ownership of the body and its parts; the fair distribution of resources and the value of the body in a biotechnologically-driven setting are representative of the nature of lengthy and detailed discussion in attempting to address those ethical sensitivities and complexities. What follows in this chapter from the wealth of material that exists therefore is an illustrative rather than exhaustive account of these very issues.

A 'live' topic for debate in the UK, the ethics of organ donation and transplantation has been placed high on the bioethical agenda since the late 1970s after the publication of Beauchamp and Childress's notable bioethical text in Georgetown USA.[226] For the last twenty years or so however attention to bioethical matters has increased exponentially as a consequence of the meteoric advancement in biotechnology. Such technology has revolutionised the way in which the human body can be successfully manipulated in order both to improve and to extend the lifespan of those whose lives ordinarily would have been seriously curtailed by life-threatening disease. There is no doubt that organ donation and transplantation is little short of miraculous in comparison with the medical possibilities of just fifty years ago as shown in the timeline in the Appendices. Nevertheless ethical unease continues unabated as a result of medical advances in technology that offer more possibility for greater sophistication in surgical technique.

The chapter begins with an evaluation of one of the most hotly debated ethical problems in transplantation medicine that relates to the difficulty of consent as it affects patients, donors and relatives alike. Consent continues to be a thorny issue because of the enduring shortage of organs for transplantation globally and the varying regulations across different jurisdictions affecting methods for coping with such a dearth of bodily material.

Consent

The concept of consent already discussed in Chapter 3 has been shown to be complex and contested. As biotechnology progresses it will become ever more state-of-the-art requiring levels of understanding hitherto unimagined. Whilst many methods obtain, most concern revolves around two specific areas of consent namely: presumed consent and informed consent. Consent is multi-faceted, not only being subject to the decisions of the donor and the recipient and in certain circumstances to the relatives, but also subject to the law. The difficulty lies in an increasing tension between the requirement to generate sufficient body parts for those in need and the rights of individuals or their families to control the use of such materials. As Nuffield's 2011 Report confirms[227] and Price points out:

[226] Since the first publication of Tom Beauchamp and James Childress's text *Principles of Biomedical Ethics* in Georgetown USA in 1977: Beauchamp, T L., & Childress, J F., (2013) *Principles of Biomedical Ethics*, 7th edition, Oxford University Press, New York, p vii.
[227] Nuffield Council on Bioethics (2011) Ch.2.

> The need to satisfy the relevant demands for body parts cannot entirely justify a donation policy in itself, although it is recognised that a failure to satisfy those needs is not only a major moral deficiency, but will invariably lead to more and more extreme means of dealing with the deficit.[228]

Indeed as Wales formally adopted presumed consent at the beginning of 2013 it is once more at the forefront of ever increasing argument and discussion. Questions concerning the influence that Wales might exert over the potential position of the rest of the UK where it is in line for writing into law, continue to be asked by theological and lay organisations alike.[229]

Presumed consent

Presumed consent refers to the routine acquisition of organs extracted from the bodies of deceased persons. It is one of the main if not *the* most contentious ethical issue in the donation of an organ/s and is seen by many as wresting control from the person whose organs they are. Furthermore presumed consent frequently places undue pressure on relatives who may be asked to make sensitive decisions concerning a loved-one who has just died.[230]

In the UK, the terminology referring to the principal systems involving consent to donate, is known as either opting-in or opting-out, see Chapter 3. Opting-in specifies that the donor has signed-up to the donor register, and opting-out is analogous with presumed consent. Opting-out assumes that unless explicit objections are raised organs will be routinely recovered from deceased persons. Such terms are very basic expressions of a highly complex area and in the case of opting-out appear to be particularly confusing to some members of the general public.[231] Alternative terminology, however, is hardly an improvement. Beauchamp and Childress have suggested a typology based on *express, tacit, implied* and *presumed consent*, which at first sight may appear to offer more clarity. *Express* consent means that the prospective donor has given explicit consent by signing-up to a register of donors and as such is quite straightforward. However the difference between *tacit* as silent agreement where no uniform lack of objection constitutes consent and *implied*

[228] Price, D., (2009) p3

[229] See BBC Wales media commentary by the Archbishop Of Wales: Drop Organ Law, September 2011, www.bbc.co.uk/news/uk-wales-14998726 accessed 03/10/2013.

[230] The refusal rate is around 40% and is perceived as a major contributor to organ shortage according to BMA Report 2012: Building on Progress: where next for organ donation policy in the UK? www.bma.org.uk

[231] Opting out as presumed consent appears to contradict the traditional sense of a refusal to join. A quote from a BBC news article in April 2013: 'I won't be a donor and will opt out asap if the law changes; my view is that it's just wrong full stop, I have made my feelings clear to my family, I don't ever want someone else's organ and I will be taking mine with me for the worms to have etc...' clearly shows the confusion, see comment no.52 at www.bbc.co.uk/news/health-22086086, accessed 30/04/2013.

or *implicit* - where consent to one medical procedure may be implied in consent to a host of further procedures within the same treatment programme, may be adding unnecessary levels of complexity and furthermore stretching trust levels rather far. In fact trust levels in medical care in the UK are under severe strain and scrutiny.[232] Additionally Beauchamp and Childress's concept of *presumed consent* 'reduces to either *express* or *implied'* on the understanding that a person's choice or values are known. However, there are cases where neither the choices nor the values of the individual *are* known, and here the problem of obtaining consent from relatives remains. Research findings reveal that relatives are very likely to refuse donation.[233] An over-complicated system may in the end prove to be unhelpful and indeed Price points to the necessity of establishing just what type of presumed consent system should be put in place. He asserts that *tacit, implied* or indeed *imputed* is a 'messy compromise' to a straightforward, non-onerous, easy and reliable way of making individuals' views known, particularly in terms of registering refusal.[234] The question would seem to be that even if the terminology were changed in some way to offer 'more clarity' or indeed to ameliorate the difficulty that the word 'presumed' presents, the stark reality is that many regard any hint of presumed consent as compromising the autonomy of the individual. It is the underlying ethos that attracts their disapproval thus perpetuating the problem of organ shortage and therefore exerting some influence on the manner in which any discussion or policy-making may play out.

Some claim that at the heart of the debate lies the question of whether a 'presumed' consent is any type of real consent at all. Janet Saunders for instance remarks that presumed consent is an affront to the moral principle that is the foundation of consent itself.[235] And Hugh McLachan states:

> To say that it can be reasonably presumed that we consent to donate our organs if we do not specifically say that we do not consent is absurd. It is a deceitful piece of sophistry. There might be a good utilitarian case for having an opt-out rather than an opt-in system of organ donation. However, this would mean that there is a case for using our organs even in the absence of our consent. If consent matters in this area, then only the explicit consent of the people concerned can justify the using of

[232] See the results from the public enquiry chaired by Robert Francis QC Report of the Mid Staffordshire NHS Foundation Trust, February 2013 covering lack of patient care in hospitals in the region, www.gov.uk/government/publications/ accessed 20/04/2013, and Understanding NHS financial pressures: how are they affecting patient care? Report published in 2017 by Robertson, R., et al, examining financial pressures on patient care across four different parts of the health system, covering genito-urinary medicine, district nursing, elective hip replacement services and neo-natal services, www.kingsfund.org.uk/publications accessed 20/09/2017.

[233] Beauchamp, T L., & Childress, J F., (2009) pp107-108

[234] Price, D., (2009) p163

[235] Saunders, J., Evidence to the National Assembly for Wales, at www.assemblywales.org paragraphs 13-14, accessed 10/02/2013.

> their organs after death. If consent does not matter and the use of their organs can be justified without it, then consent does not matter….[236]

In contrast, certain advocates of presumed consent maintain that the dead have no interests at all after their demise and therefore whatever interests that do exist, are outweighed by the undeniable and immediate interests of those requiring such materials to improve their health and quality of life. Spital and Taylor argue that even if there is concern about posthumous harm 'routine removal of usable cadaveric organs is the way to go.'[237] In comparison, Harry Emson's perception is of a process of natural recycling of human body parts into future generations through decay, decomposition and transference, and therefore the right control over the body should be vested in the state as representative of those who may benefit from organ donation.[238] In agreement with Emson, Walter Glannon maintains that 'the idea that the sick have a right to cadaveric organs is grounded partly in the belief that these organs are no longer of any use to the dead. Hence viable and therefore useful body parts can be treated as state property.'[239]

Countering the claim that presumed consent would compromise personal autonomy the BMA and the NHSBT reason that a culture in which donation is discussed more openly and perceived as the norm would benefit those who have a strong objection to donation since it would make clear their wishes before their death. Any absence of a system such as presumed consent prevents discussion having taken place and thus reduces autonomous decision-making. It also aggravates the situation where relatives are left with the burden of decision-making when they might be less able to think clearly and more likely to refuse.[240] In fact we might question whether there is indeed a 'right' time and place for these discussions to take place together with the real risk that people might die unexpectedly before decisions about donation have been confirmed.

As part of its commitment to implementing presumed consent, the BMA are also seeking to secure permission for ventilation. Ventilation ensures that organs arrive in a healthier state for transfer to recipients and time is no longer of the essence in certain procedures such as heart transfer, thus recipients stand to benefit in the long term. As a result of ventilation there is the likelihood of a more successful outcome and a much improved prognosis for

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[236] McLachlan, H., (2008) Presumed consent is no consent at all, www.bmj.com/cgi/eletters/336/7636/111-a#188146

[237] See Ch.3 p71 of this study.

[238] Emson, H E., (2003) It is immoral to require consent for cadaver organ donation, *J Med Ethics*: **29:3:125**

[239] Glannon, W., (2003) Do the sick have a right to cadaveric organs, *J Med Ethics*: **29:3:153**

[240] BMA (2012) Building on Progress: Where next for organ donation policy in the UK, pp45-46.

recipients together with positive implications for transplantation in general in the future. However, ethical questions remain over this procedure. While the BMA argue that ventilation presents a further opportunity for relatives to say goodbye to their loved-ones, reports from relatives suggest that it is difficult for closure to be had whilst the body of their loved-one appears still to be alive when they leave which can add to their distress at the time.[241] In whatever event, it is the responsibility of the medical teams involved to honour the wishes of the deceased and their relatives.

Evidence shows that ethical challenges to any decision to implement presumed consent are varied. Discussions reach far beyond the pragmatic and rational into the realms of personal preference, day-to-day issues and themes relating to selfhood. Roger Goss has commented that presumed consent runs counter to the principle of protecting patients' rights to fully informed agreement, and it 'clashes with the prevailing practice to involve patients fully in treatment decisions.'[242] Veatch and Pitt for instance believe that presumed consent is based on an erroneous assumption that people would donate if asked, claiming that the desire of many to acquire more organs might stifle the wishes of religious minorities for instance who find organ and tissue donation morally problematic.[243]

Ann Sommerville, points to real life dilemmas that tend to include inconsistencies, opposing desires, ambiguities and 'ragged-edges.'[244] And O'Neill suggests the focus of bioethical discussion relating to autonomy:

> ...is not on patient autonomy or individual autonomy of any distinctive sort. What is rather grandly called 'patient autonomy' often amounts simply to a right to choose or refuse treatments on offer, and the corresponding obligations of practitioners not to proceed without patients' consent.[245]

Equally, Daniel Sperling comments that: 'The act of organ donation should be regarded as enhancing the autonomy and self-expression of the donor and expanding - not abolishing - the self.'[246] In contrast to Sperling's thesis, certain philosophies would hold that an

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[241] BMA (2012) Building on Progress: Where next for organ donation policy in the UK, p27. The Guardian: Doctor's radical plan to tackle organ shortage, February 13th, 2012, www.the guardian.com/society/feb13, accessed 15/02/2012.
[242] Goss, R., (2000) Presumed consent further undermines medical ethics. *British Medical Journal*: **321:7267:1023**
[243] Veatch, R M., & Pitt, J B., (1995) 'The Myth of Presumed Consent: Ethical Problems in New Organ Procurement Strategies', *Transplant Proceedings*: **27:2:1888-92**
[244] Sommerville, A., (2003) Juggling law, ethics and intuition: practical answers to awkward questions in *J Med Ethics*: **29:281-286**
[245] O'Neill, O., (2002) *Autonomy and Trust in Bioethics*, Cambridge University Press, Cambridge, pp37-38.
[246] Sperling, D., (2008) Me or mine? On property from personhood, symbolic existence and motivation to donate, in *Organ Transplantation: Ethical, Legal and Psychosocial Aspects*, edited by Weimar, W., Bos, M A., and Busschbach, J J., Pabst Publishing, Lengerich, p470.

individual possesses interests after death and death is just a different conceptualisation of the form in which persons exist.[247] Sperling retorts however that even after death organ donation represents an expression of the recognition of a person's 'symbolic existence' in non-material, second-order terms.[248] In other words the donor maintains a link with the living person who holds all human interests belonging to the former person whose interest they are. And Mark Wicclair further agrees that we should not see death as signifying the total 'annihilation of all moral traces' of the person who once was.[249]

Would we accept a view that the human body in receipt of another's organ has somehow been transformed into a hybridised form - a kind of synthesis of two people at the level of 'sharing' an organ, and what would be the legal and ethical ramifications should we think of the body in this way? It is not an issue that has been comprehensively debated in recent years, but nonetheless has received significant attention and whilst not the central remit of this study warrants further analysis.[250] Indeed the anthropologist Lesley Sharp carried out some research that revealed that 'encounters between donor kin and organ recipients generate shared understanding of unusual forms of embodied intimacy.'[251] She maintains that this indicates '...a bio-sentimentality, for organ recipients are frequently understood as experiencing remarkable transformations by virtue of their harbouring within them the body fragments of organ donors.'[252] As she argues this extraordinary outcome has the potential to transform the recipient's sense of self 'into a gestalt composed of the ego merged with another.'[253]

Having legalised presumed consent, European countries such as Spain and Belgium report success. Apart from Wales however, the remainder of the UK has continued to investigate the possibility of such a move. In sanctioning presumed consent, Wales anticipated that a 25% increase in donation rate would result post legalisation.[254] This could be seen as encouraging for those waiting for an organ as a result. However in 2016 a year after The Human Transplantation (Wales) Act 2013 became extant, statistics reveal that the figures for deceased as well as living donors are still very low compared with the overall population:

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[247] See Ch.2 of this study.
[248] Sperling, D., (2008) p470.
[249] Wicclair, M., (2008) Ethics and research with deceased patients, *Cambridge Quarterly of Healthcare Ethics*:**17:87-97**.
[250] See Ch.8 of this study.
[251] Sharp, L A., (2006) *Strange Harvest, Organ Transplants: Denatured Bodies and Transformed Self*, University of California Press, Berkeley and Los Angeles, California, pp198-199.
[252] Sharp, L A., (2006) pp198-199
[253] Sharp, L A., (2006) pp198-199
[254] BBC News: Wales organ donation opt-out: Health committee backs Bill with reservations, www.bbc.co.uk?news/uk-wales accessed 25/03/13.

total deceased donors over the period 2015-2016 amounted to 64, and total living donors amounted to 30. In the period 2016-2017 those figures for deceased donors dropped to 61, but increased to 36 for living donors. The total difference shows no statistical significance between the two periods.[255] Yet for 2016-2017 the number of patients on the active waiting list in Wales rose by some 43 patients over the previous period and overall transplants dropped to 187 from 214 the previous year.[256] Despite this seeming lack of progress in Wales, The Guardian newspaper reported that in February 2018 in Britain the first vote to legalise the automatic usage of organs post mortem was passed. A first hurdle that it has to be said shows little evidence and scant rationale - given Wales' experience - for increasing the potential saving of lives to 200.[257] Ministers in Scotland also have announced plans for moving to a 'soft opt-out' scheme in the future.[258] It must be borne in mind however that writing presumed consent into law is merely one step towards overcoming the problems of gaining approval for organs to be donated or indeed transplanted. Informed consent equally plays a major part for both donor and recipient alike.

Informed consent and the doctor patient relationship

In the matter of patient or recipient consent, Neil Messer considers the relationship between physician and patient to be paramount, since at the heart of healing is the *caring* undertaken by doctors and other health professionals towards the patient and those close to them.[259] Development of trust is crucial in what is an unequal relationship where patients ultimately depend on an expert to provide answers to their health problems at a time when they are least able to cope. Such reliance has implications for patient autonomy, informed consent and ultimate decision-making.

In particular cases such as organ transplantation, major difficulties with relating information to those who have little concept of the intricate, technical, nature of that which they are about to undergo becomes ever more concerning as biotechnology advances. A cursory glance at the specialist articles in the Lancet is proof positive of the linguistic complexity involved and highlights the problems of a 'private' language that is accessible to a very

[255] See BBC News: Wales' organ donation opt-out law has not increased donors at www.bbc.co.uk/news/uk-wales accessed 15/01/2018.
[256] NHSBT (2017) Organ Donation and Transplantation Activity Data: Wales, March 2016-April 2017.
[257] The Telegraph (2018) Theresa May and Jeremy Corbyn back plans to make organ donation automatic in England as new law clears first major hurdle, 23rd February 2018.
[258] The Guardian (2017) Organ donation presumed consent could be adopted in England, 30th June 2017.
[259] Messer, N., (2002) (ed.) *Theological Issues in Bioethics, An Introductions with Readings*, Darton, Longman & Todd, London, p153.

limited section of society. This results in the skills and language used by the physicians far surpassing the understanding of most patients thus rendering their position increasingly vulnerable and undermining the vital dual control that this relationship demands. As a result the possibility of medical paternalism increases as advances in and uses of ever more complex biotechnological language progresses that effectively compound the distancing of the patient from their own body and bodily identity.

The loss of the traditional relationship between the family doctor and the patient may constitute part of the difficulty in establishing consent. In former days, a level of trust was built up over numerous years with the family doctor who treated patients with full knowledge of their and their families' medical history and circumstances. According to Karen Lebacq, the doctor represented some stability in a world where the patient felt powerless and a certain loss of 'normal' status in the world.[260] On this matter O'Neill advises:

> The traditional construction of doctor-patient relations as relations of trust, as quasi-personal, as guided by professional concern for the patient's best interests makes sense to many patients because (if achievable) it would secure what they most need. The point and the context of the older, trust-centred model of doctor-patient relationships are not at all obscure….Contemporary relations between professionals and patients are constrained, formalised and regulated in many ways, and may erode patients' reasons for trusting.[261]

Presently, therefore, not seeing the same doctor and the dual constraints of time and finance together with more complex health problems conspire against such traditional ways of treatment. Patients are often necessarily seen by a team of professionals in both medical and other capacities on a one-to-one basis over a protracted length of time, and this can add to their feelings of instability and disempowerment and furthermore can lead to a slower rate of recovery.[262] Nowhere is the problem of lack of good and consistent communication more amply demonstrated than when things go wrong. The Alder Hey case is a prime example of the trauma that can ensue when good communication breaks down and trust is abused in such professional/patient relationships.[263]

In the UK two key issues have emerged illustrating the need for greater trust between patients and their clinicians. A patients' association report in 2012 gave details of a survey of

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[260] Lebacqz K., (2002) Empowerment in the Clinical Setting in Messer, N., *Theological Issues in Bioethics*, Darton Longman & Todd, London, pp173-174.
[261] O'Neill, O., (2002) pp38-39
[262] O'Neill, O., (2002) pp38-39
[263] Bauchner, H., & Vinci, R., (2001) What have we learned from the Alder Hey Affair? *British Medical Journal*: **322:309-310**

a considerable sample of patients showing a significant drop in satisfaction, trust and involvement in care.[264] And the Francis Report into the Mid Staffordshire NHS Trust debacle, made recommendations to shift the emphasis from a focus on business issues to once more placing the patient at the forefront of healthcare.[265] Revival of the values of truthfulness, trust and care - considered lost as a result of prioritising business issues over patients - are perceived to be distinctly more important in achieving greater successful end results both for the patient, not to speak of the reputation of healthcare authorities.

Patient choice moreover is seen as imperative in establishing informed consent, and there have been several proposals considering how patient autonomy may be safeguarded. For example Beauchamp and Childress claim that a structured approach with a checklist of elements to be gone through and approved will alleviate the problem of breakdown in communication.[266] Manson and O'Neill argue that some form of negotiation between physician and patient as shared communication could be considered legally or morally sufficient.[267] Whatever position is adopted, the standing of patients has to be made clear in order to provide the binding contract covering that which they are about to undergo without leaving them in a state of feeling disconnected or helpless.

Of clear importance is the concept of informed consent as a standard way of avoiding breaches of significant obligations. It is ethically important in medical practice where interventions would otherwise contravene underlying responsibilities. Rights exist which cover considerably more comprehensive aspects for patients than merely protection of their autonomy. As Manson and O'Neill point out: both in medical practice and research, informed consent practices presuppose the very significant ethical, legal and professional obligations not to invade others' bodily integrity, not to constrain their liberty of action, not to deceive them or to violate their privacy or indeed any rights that correspond to these duties.[268]

> We cannot have medical or research intervention unless we permit limited action that would otherwise constitute a breach of bodily integrity, personal liberty or privacy; informed consent is a way of granting permission for such action. It is not,

[264] Primary Care: Patients and GPs - Partners in Care Sept 2012. From a survey of 10,000 patients there was an increase of 69% in the number of complaints made against doctors since 2009. The fastest growing concern was around communication skills and rudeness. 80% of patients said they wanted to be more involved in their care, pp 3-4.
[265] Mid Staffordshire NHS Foundation Trust (2013) pp 4-5
[266] Beauchamp, T L., & Childress, J F., (2009) pp120-112
[267] Manson, N C., & O'Neill, O., (2007) *Rethinking Informed Consent in Bioethics*, Cambridge University Press Cambridge, p187.
[268] Manson, N C., & O'Neill, O., (2007) p187

> and certainly not primarily, a way of exercising individual autonomy, however conceived.[269]

Equally for the living donor informed consent is closely interrelated with pragmatic concerns of relating sufficiently understandable material that clarifies the risks of surgery and the likely health and everyday practical implications of undertaking such a serious procedure.[270] After all, the living donor who was formerly extremely healthy will effectively become a patient with all that entails. In fact Price remarks that some critics maintain that living donation is an illegal practice that contravenes the moral and ethical prescription of non-maleficence.[271]

In a healthcare system that paradoxically is supremely advanced and well equipped to undertake sophisticated transplant procedures people continue to die on a daily basis through the acute shortage of organs, the reasons for this shortage are manifold. The reality is that people's health has significantly improved over the last fifty years leading to an ever-aging population whose organs on their death are unlikely to be fit for transplantation. And fatal accident rates have dropped overall in the last few years with the introduction of stringent seat belt and drinking laws, although exceptions remain in the case of young, new drivers' serious accident rates.[272] Whilst overall donor refusal rates continue to remain persistently high and in contrast numbers on the donor register have considerably improved, the needs of those on the transplant list are far from being met.[273]

There is little doubt that the concept of donating an organ is ethically problematic. For the donors it requires some extremely serious thought concerning how we perceive our bodies and how we wish others to perceive us. It is no trivial exercise involving considerable rational as well as emotional input for the individual donor and some very careful and powerfully persuasive arguments from those who wish to encourage people to donate in the first place. For instance are we altruistically inclined to donate an organ as a gift of such magnitude? Are we truly capable of such extreme generosity?

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[269] Manson, N C., & O'Neill (2007) p188

[270] Many specialist hospital units provide booklets for donors of varying degrees of pragmatic and anatomical information. Addenbrooke's has a publication Living Kidney Donation: Your questions answered.

[271] Price, D (2009) p197 note 4

[272] It remains to be seen whether the mandated question on the drivers' licence application will alleviate this problem, but it must be borne in mind that relatives are still in a position to override whatever decision has been recorded. See Nuffield Council on Bioethics (2011).

[273] See the Introduction and Background to this study.

Gift giving and its interrelationship with altruism

The notion of the gift is seen as vital by organisations in the donor-organ relationship.[274] The word 'donor' equally reinforces the concept of an act of charitable gift-giving. Catherine Waldby and Robert Mitchell criticise the gift metaphor as demanding altruism, ceding of control for donors, obscuring the potential value of tissues and rendering the body an 'open source of free biological material for commercial use.'[275] Equally, Nancy Scheper-Hughes has alluded to the 'tyranny of the gift' alleging that even living related donation is more accurately described as 'poaching' than a voluntary act of giving.[276] On the other hand Grant Gillett believes that the notion of the 'gift of oneself' parallels the highest ideals of most moralities, both secular and religious and equally in ethical terms and public image.[277] And as Graeme Laurie states 'The notion of the gift has a strong normative appeal.... It is in our nature generally to offer a helping hand to others in need.'[278]

Somewhat unconvincing however, is the idea that the gift of an organ has certain equivalence to the gift of life.[279] More accurate may be the idea of the gift of an improved level of health, or the gift of an extension to life, although these too come with certain limitations. Whereas the gift of life idea may be the perspective of organ recipients or their relatives since the reality for them is that precious lives are indeed being saved, the very notion needs to be balanced against what kind of life this turns out to be. It is not a life restored to its former self. For many recipients organ transplantation only buys time and requires adjustment to a lifestyle of dependency on drugs and other attendant health problems which can arise, or indeed the likelihood of further transplantation at some later date.[280] In fact Laura Siminoff and Kata Chillag allege that the donor is often the 'gift object' as opposed to the gift giver, and further that the concept is 'used' by healthcare professionals as a form of social control diverting attention from other ethical issues such as

[274] See Nuffield Council on Bioethics (2011)
[275] Waldby, C., & Mitchell, R., (2006) *Tissue Economics: Blood, Organs and Cell Lines in Late Capitalism,* Duke University Press, Durham, p24.
[276] Scheper-Hughes N., (2007) The tyranny of the gift: Sacrificial violence in living donor transplants, *American Journal of Transplantation*: **2007:7:507**
[277] Gillett, G., (2000) Ethics and images in organ transplantation in *The Transplant Patient: Biological, Psychiatric and Ethical Issues in Organ Transplantation*, Trzepacz, P. & Dimatini, A., (eds.) Cambridge University Press, Cambridge p.239.
[278] Laurie, G., (2002) *Genetic Privacy, A Challenge to Medico-Legal Norms*, Cambridge University Press, Cambridge p312.
[279] Often quoted on organ donation websites such as that of NHSBT.
[280] See NHSBT Organ Donation and Transplantation Activity Report 2011 re-transplant rates.

the quality of life after transplant and the possibility of the need for further transplantation.[281]

Paradoxically, however, the UK organ donation system is based solely on altruism and the gift relationship. In this matter, the BMA consider that the gift element of donation can be important to those families who consent to donation and to those who receive organs. In refuting an assertion that if an individual either personally or via relatives pro-actively volunteers an organ it is no longer a gift, they give quite a convoluted argument:

> Under an opt-out system individuals go through exactly the same thought process as they do in deciding to opt-in. Given the option to donate or not, a decision is made to act to help others, by not opting out of donation, this is no less of a gift than an organ donated under an opt-in system…Under an opt-out system there is no way of knowing which of those who have not opted-out would have taken positive steps to donate under an opt-in system. Some people will see the loss of this positive action to donate as a cause for concern. Whilst it may be seen as preferable for individuals - or their families - to take action to give organs, we need to acknowledge that under the current system organs are being lost that could have saved lives when that would not have been the wish of potential donors….[282]

Unpicking this rather contradictory and naïve line of argument interestingly throws up the difficulty of establishing altruistic donation - yet altruism is a concept the BMA vehemently uphold. Serious misgivings would ensue in any event where decisions to opt-in were equivalent to those of opting-out, as they claim. The intellectual process might be similar, but the emotional impact would be different by orders of magnitude.

There is no doubt that to verify that an organ has been given totally without any ulterior motive is particularly problematic. This is of real concern in cases of living altruistic donation, since people rarely come forward unprompted to offer an organ, in fact in the UK only 80 so-called live altruistic donors made such an offer in 2016/2017.[283] The burning issue remains to prove in cases of organ donation that any perceived charitable act is indeed altruistic.

The notion of altruism in organ donation

Biological altruism for instance explains how unselfish behaviour might have evolved. However it implies nothing about the motives or intentions of the agent. Christine Clavien

[281] Siminoff, L., & Chillag, K., (1999) The fallacy of the 'gift of life', *Hastings Center Report*: **29:6:34-35**
[282] BMA (2012) Report: Building on Progress: where next for organ donation Policy in the UK, p49.
[283] NHSBT Organ Donation and Transplantation Activity Report for 2016-17, www.nhsbt.nhs.uk

and Michel Chapuisat claim that altruism is a deep and complex phenomenon, confusing because the term covers variable concepts and processes across disciplines and is thereby context dependant.[284] And Judith Lichtenberg maintains that despite evolutionary theories the commonly held view that people never intentionally act to benefit others except to obtain some good for themselves still possesses 'a powerful lure' over our thinking.[285]

Situations do arise when we appear to act unselfishly, because other reasons for our behaviour often come into play: the prospect of a future favour in return, the boost to our ego and standing in the community, or simply the good feeling that comes from appearing to act unselfishly. Whether or not the donor is truly offering an organ altruistically is questionable since statistics demonstrate that live donation is directed in favour of a relative or friend in many cases, leaving open to question whether altruism is indeed relevant or even a necessary criterion at all. The important point about the notion of gift is that it is mandated to ensure that no money is exchanged. Douglas Martin and Eric Meslin consider that the lack of potential reciprocity generates dissonance in relation to organs and constrains levels of donation in so far as it may not be reasonable to expect a person to make a gift of such magnitude in an entirely detached and impersonal context.[286]

The concepts of altruism and the sanctioning of a so-called acceptable form of payment were considered by Nuffield in their 2011 Report.[287] In response to continuing organ scarcity and low donation rates, Nuffield chose to focus on altruistic gift-giving relative to fair and acceptable incentivisation schemes such as payment for peripheral expenses, clearly in the hope that this might increase the pool of donors, see **Figure 1:**

[284] Clavien, C., & Chapuisat, M., Altruism across disciplines: one word, multiple meanings, *Biology and Philosophy*: **28:1:125-140**

[285] Lichtenberg, J., Is Pure Altruism Possible, *The Stone* 19th October 2010.

[286] Martin, D K., & Meslin, E., (1994) The give and take of organ procurement*, Journal of Medicine and Philosophy:* **19:1:61-78**

[287] Nuffield Council on Bioethics Report (2011): Human Bodies: donation for medicine and research, Ch.6.

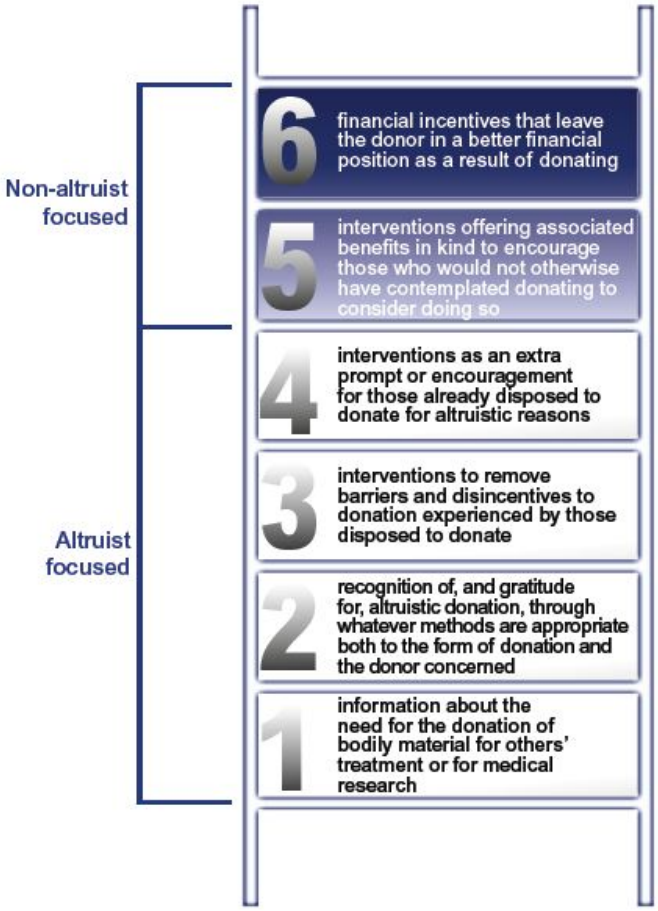

Figure 1: The Altruism Ladder proposed by Nuffield[288]

What constitutes 'fair recompense' to the donor who in many cases may be the only person concerned *not* to receive any form of remuneration? The question lies in contrast to the salary paid to health care staff involved, or the direct benefit the recipient derives as a considerable health benefit from the donated material. Such questions arise especially where the intermediaries concerned in the process - for example the medical teams and the pharmaceutical companies who operate on a commercial basis - gain sizeable financial reward.[289]

As a supporting exercise for part of their 2011 study, Nuffield conducted a small ad hoc survey to test out attitudes to the acceptability of diverse kinds of incentive and further to give some credibility to the tool they developed.

[288] Nuffield Council on Bioethics (2011) Ch.6
[289] Nuffield Council on Bioethics Report (2011): Ch.5

The responses however were somewhat indifferent.[290] Furthermore, however well-intended and creative their ladder concept is, it does send out a rather mixed message which appears contrary to the much held ethical principle of the necessity for a benevolent act of gift giving, of giving for giving's sake.

Further questions arise concerning the reliability of a tool that is essentially reductionist that will aid in assessment of such a multi-dimensional problem. What results are expected in relation to the goal of increasing donor rates? What happens if a particular case does not fall neatly into any one of the criteria? In light of the responses received in Nuffield's ad hoc survey, how would the ladder be adapted to meet the needs of those who would be in receipt of 'associated benefits in kind', or some acceptable financial benefit for having donated? These matters would need to be thoroughly examined together with issues relating to those who refuse to donate, and subsequently need a transplant, in order that precedents are not set so that those who do refuse are in no way disadvantaged by those who donate, such as funeral expenses or precedence on waiting lists for a donor organ.

Donating any organ is a personal decision dependent upon a very complex set of circumstances which might occur at any time during an individual's lifetime: for living donors it means undergoing risky surgery and being suitable to do so together with the attendant health issues post-operatively. For the deceased or their relatives - openness to the idea of being buried with a loss of bodily integrity, and for those with certain religious inclinations its acceptability. All are certain to be amongst the most searching issues both relatives and prospective donors will have to face. Any talk of incentive may be far from their immediate priorities when making such decisions.

Would any form of payment incentive or otherwise be considered appropriate in the context of organ donation? Is the insistence on altruism and gift giving justifiable when people are dying through lack of a much-needed resource? Would financial incentive lessen acts of trafficking and alleviate a global problem? Are the difficulties merely practical or are deeper

[290] An ad hoc survey of 499 respondents was conducted by an independent working party to investigate how effective incentives were considered to be for donating bodily materials. The five incentives suggested were: a letter of thanks, a donation to a charity, a token payment, a substantial payment and a payment in kind. The forms of donation considered were joining the Organ Donation Register (ODR) to donate organs after death, and donating sperm or eggs to help a childless couple. Results concluded that: 80% of respondents were comfortable with organ donation, and less than half were actually on the ODR; payment of all sizes for all donation types were seen as unethical and ineffective by a majority of respondents; payment in kind was seen as more ethical and more effective than payment in money; donation to charity and letter of thanks were viewed as ethical, but not necessarily effective incentives.

concerns such as how we view and value the body part of the problem? Some form of payment is nonetheless a consideration, however its acceptability is another matter.

The payment debate and the issue of commodification

Payment *per se* for either selling or acquiring organs is illegal in the UK. The move towards any kind of payment is not without difficulty for as Cynthia Cohen points out:

> [The] reason we are reluctant to exchange money for human kidneys is that this would deny something distinctly valuable about human beings - their dignity and human worth....Our body has special value because it is the medium through which we express ourselves. Thus, our special value as human beings extends to our bodies.[291]

Moreover, Mark Cherry argues that the more the conceptual distance between persons and their body parts is increased, the more body parts become like other objects in the world to be possessed, given away or sold.[292] This would seem to suggest that any concept of trading could be linked to some notion of the closeness of various body parts to identity and 'self.' Indeed Immanuel Kant in *Lectures on Ethics* viewed it inconceivable to imagine a life not mediated by the body.[293] And Campbell states that dismantling the body in order to earn money raises some serious issues about personal integrity, since the body is being treated as a permanent and alienable commodity.[294]

According to Janet Radcliffe-Richards, the problem is not the idea of payment itself, but in how the case is argued.[295] Payment is something we do for goods and services on a regular basis - it is not anathema in the ordinary sense of the word. The underlying justification needs to be one of balancing the benefits and risks of sanctioning any form of payment. Some doctors argue that payment for organs or transplantation leads to a slippery slope position which privileges the wealthy. Whilst this is admittedly a general point that is often made against those who can afford to 'go privately', it nevertheless has some validity in this context. We might question why organ donation and transplantation should be considered

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[291] Cohen, C., (1999) Selling Bits and Pieces of Humans to make Babies: The Gift of the Magi*, Journal of Medicine and Philosophy*, **24:3:291**

[292] Cherry, M., (2005) *Kidney for Sale by Owner: Human Organs, Transplantation and the Market*, Georgetown University Press, Washington, p26.

[293] Kant, I., (1963) *Lectures on Ethics,* Infield, L., (trans), Harper & Row, New York, pp147-148.

[294] Campbell, A V., (2003) The virtues (and vices) of the four principles in *J Med Ethics*: **29:5:292-296**

[295] Radcliffe-Richards, J., (2012*) The Ethics of Transplants: Why careless thought costs lives.* Oxford University Press, New York, Ch.2.

any differently. What is it that peculiarises this sphere of medicine and therefore incurs this type of comment?

On the one hand there are those who argue that payment for organs could drive up the rates of donation, lessen the problem of trafficking and transplant tourism and more importantly offer the hope of improving the lives of those who are desperately in need of an organ/organs.[296] On the other, it is felt that payment for organs could lead to a situation where market forces dictate price differentials between organ types. In the opinion of Childress the various arguments associated with payment are not convincing enough to prove that the act of selling an organ is intrinsically immoral.[297] Whereas Gillon believes that while in individual cases selling an organ such as a kidney may be entirely justified, nonetheless the likely dangers of financial exploitation and post-operative harm to predominately poor individuals involved in the transactions would probably result in an excess of harm over benefit.[298] Yet again there are those who would vehemently disagree with each and every one of the foregoing points.[299]

The issue of payment remains controversial since there is a delicate balance to be struck between benefits and harms if some form of remuneration were to be agreed. Continued problems in overcoming scarcity encourages more and more extreme levels of dealing with the issue as Price has pointed out. There are those who may be likely to benefit financially from selling an organ, for instance people in the poorest nations who donate organs for their own day-to-day survival. There is however a real danger that they are likely to be exploited and are not in a position to access the follow-up care required after major surgical intervention. Indeed as Price points out, transplant tourism and the likelihood of trafficking, potentially increases the more this situation continues.[300]

It has been suggested that some global legal framework might be a solution.[301] However this is very unlikely when in many countries payment for organs is considered both unacceptable and illegal and gaining agreement would prove particularly problematic where payment for

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[296] Kluge E-H W., (1999) Organ Donation and Retrieval: Whose Body is it anyway? in Kuhse, H., & Singer,P., (2006) (eds.) *Bioethic: An Anthology*, 2nd edition, Blackwell Publishing, Oxford, p483.
[297] Childress, J., (1992) My body as property: Some philosophical reflections, *Transplantation Proceedings*: **24:5:2144**
[298] Gillon, R., (2003) Four scenarios, *J Med Ethics*: **29:267-268**
[299] Radcliffe Richards et al in: Kuhse, H., & Singer, P., (2006) (eds.) *Bioethics: An Anthology* 2nd edition, The Case for allowing Kidney Sales, Blackwell Publishing Ltd., Oxford, pp487-490.
[300] Price, D., (2009), pp16-19
[301] See Organs for Transplant (2008): Report: The Organ Donation Taskforce: Recommendations, p36, www.webarchive.nationalachives.gov.uk

medical care is routine. Unfortunately the outcome of this impasse results in persistent scarcity of organs and limited hope to those waiting on any transplant list.

Since many forms of payment or incentivisation continue to incur considerable criticism and relentless debate and discussion, the question of ownership has been considered as a policy which in Price's terms will 'cut through the increasing noise' provided by legal and ethical principles which inevitably operate in a 'fuzzy' way.[302] Why should I not demand some form of recompense for giving away something that ostensibly is mine? The question is however do we 'own' our bodies in the same way as we might own for instance a house or a car that we would inevitably sell in return for some pecuniary exchange? Or is ownership of the body an ethical matter to be considered on a totally different basis?

Ownership

Veatch et al contend that defenders of donation hold that organs from the deceased are not for the taking, whilst advocates of incentives are unconvinced of any notion of property rights.[303] The question here is whose body is it? As a lawyer, Price favours the clearer cut approach of ownership which involves a type of legalisation of property rights in order to bring control back to the donor, which he maintains is the only way to ensure faithfulness of the gift. Whilst the donor may have no expectation of the return of bodily material, there is an expectation that it will be used in accordance with the 'terms' of the gift.

With ownership, however comes risk as Price suggests:

> ...[of] course [ownership]might lead to perceptions of finance and market driven forces, with illegal money changing hands and the facilitation of exclusive control and unfettered use and powers over such materials including use for ethically unacceptable purposes. This might not only result in perceptions of inequity, but could potentially jeopardise the trust of those who are being asked to freely donate to third parties who are then able to exploit such materials including commercially without constraints. It is therefore necessary to translate the fairly ubiquitous and popular concept of the gift into legal concepts which more faithfully and appropriately reflect the wishes of the donor.[304]

Nonetheless there is considerable difficulty with words such as 'gift' in this context. The concept of property rights however is of a different moral status to the rights accorded to

[302] Price, D., (2009) p1
[303] Veatch, R M., Haddad, A M., English, D.C., (2010) *Case Studies in Biomedical Ethics*, Oxford University Press Inc., New York, pp297-298.
[304] Price, D., (2009) pp295 -296

humankind. The notion of property or ownership in this context not only highlights the question of how humans are to be valued, but also the currently illegal market potential for body parts. In positioning his argument Price points to the reality of the possibility for misuse of bodily materials for the purposes of financial gain and the numerous cases reported globally of trafficking and transplant tourism on the one hand; [305] whilst on the other in the UK reports continue of organs freely donated on the NHS for transplant to private patients.[306]

Margaret Radin in discussing policy reform, considers that to treat personal property as marketable property is to redefine and change the character of any act of giving. It affects our understanding of ourselves and our bodies.[307] Andrews and Nelkin concur with Radin, claiming that the body not only serves certain functions for science, but also for society.[308] A person's control over what is done to his or her body, or its parts, is important to their psychological development and wellbeing. It is a means to establish identity and equally conveys values to others. Moreover, beyond the individual, social conceptions of the body establish community identification.[309]

According to Price however, failure to establish ownership creates a problem for society in general since the lack of bodily materials has the potential to 'invariably fuel more and more extreme means of dealing with the deficit...' and as a consequence will inevitably lead to a requirement for further ethical and policy decision-making.[310] Whether or not ownership is to be established by a set of rights-based regulations is appropriate, there is undoubtedly a need for a comprehensive legal and ethical approach that is perceived to be fair and transparent for those involved in the donation process. Fairness extends to the distribution of resources which given the dual constraints of finance and shortage of organs presents real-life issues for those decision-makers responsible for determining who shall receive an organ. The dilemma of relating who will remain on the transplant list or who is unsuitable

[305] Price, D., (2009) p296
[306] According to the Sunday Times 24th March 2013 article: Doctors attack cash for liver transplants, surgeons at an NHS Foundation Trust Hospital in London have transplanted 19 livers into fee-paying patients from a variety of European countries in the last two years, despite a government recommendation made 4 years ago that the practice should be banned. The organs were donated to the NHS for those in need within the British system.
[307] See President's Council on Bioethics, session 4: Organ Transplantation and Policy Reform, 7th September 2006, at www.bioethics.gov/transcripts/sept06 accessed 14/09/2011.
[308] Andrews L., & Nelkin, D., (1998) Whose body is it anyway? Disputes over body tissue in a biotechnology age. *The Lancet*: **351:9095:53-57**
[309] Andrews L., & Nelkin, D., (1998) **351:9095:53-57**
[310] Price, D., (2009*)* pp295 -296

for transplantation at all and will face the inevitability of the end of their life, remain daily occurrences in the lives of most clinicians in this specialist field of medicine.

Fair distribution of resources

Fair distribution of resources within transplantation medicine is predicated on sufficient bodily materials to 'go round' which is problematic. Indeed many discussions in this study have been focussed on measures looking to alleviate this worldwide issue. As a result of the shortage of bodily materials, medical professionals have some extremely difficult decisions to take in rationalising who will receive an organ or organs and who will remain on the transplant list or not. Should fairness extend merely to the distribution of organs for transplant to those deemed 'suitable' resulting from the application of a supposedly independent measure of quality of life post-surgery? Should those who have abused their health be entitled to the same opportunities for transplantation as those who have looked after themselves? What if I just want to live longer irrespective of age, gender or ethnicity? These are very real considerations in the decision-making process.

Due respect to the way in which the body is treated is an important consideration in issues of ethical fairness and transparency - not merely on a physiological level, as in adhering to the principles of non-maleficence and beneficence, but rather in taking into account the needs of the individual who may be feeling out-of-step with the world for long periods of time. O'Neill believes that in the domain of bioethics justice cuts across other ethical principles including those of autonomy and beneficence, and consequently appears to operate quite differently. Justice in this case is more relevant to medical policies and systems rather than to clinical decisions or doctor-patient relationships. In the context of distributive justice, justice serves as a reminder that fairness is not merely a matter of conforming to the law or a particular ethical code of practice. Rather it involves answers that demand a critical appraisal of the needs of the individual above and beyond those of a medical nature - what it is to respect and have care and concern for others at a time when they are at their most vulnerable.[311]

For healthcare and organ donation and transplantation in particular, issues of fair distribution of resources is probably the single most complex of difficulties to overcome

[311] O'Neill, O., (2002) p34-35

ethically - particularly since financial considerations are uppermost in the majority of healthcare establishments. Despite the volume of psycho-social questions for both the donor and the recipient prior to surgical intervention, in the UK allocation of organs boils down to gaining the maximum benefit for the maximum number - a principle considered ethically problematic since it prioritises the choices of the many over those of the individual. John Rawls argues that, '…it fails to take seriously the distinction between persons. The principle of rational choice for one man is taken as the principle of social choice as well.'[312] The dilemma in the case of transplantation occurs when selection of recipients rests on a choice between instances where one might offer the most benefit while another might be the most fair.

Moral conflict arises when the basis of who might have increased life expectancy and a better prognosis for recovery becomes a norm for decision-making. The question is: is allocation on this premise equitable? For organ transplantation the idea of assessing an individual on the future outcome of quality-of-life and its longevity seems particularly difficult to countenance in light of an uncertain future for any of us. Quality Adjusted Life Years (QALYs) often work against the older patient or indeed the young infant, since they are considered less likely to accrue the most benefit in terms of survival. Harris maintains that basing decisions on age is ethically problematic: 'the point is a simple but powerful one: however short or long my life will be, so long as I want to go on living it then I suffer a terrible injustice when that life is prematurely cut short.'[313]

And yet quality of life language implies that not all lives are equally good or equally deserving of protection, thus it is essentially discriminatory according to Richard McCormick. Every life being of equal value reveals a legitimate concern for instance that medical treatment is not denied or withheld in a way that violates the rights of individuals. However, perhaps that is not the concern. Every person may be of *equal* value, but not every *life* is of equal value. The terminology is of vital importance here in making ethical decisions. McCormick makes a valid point:

> If 'life' means the continuation of vital processes in a persistent vegetative state; if 'value' means a good to the individual concerned; if 'equal' means 'identical' or 'the same' especially of treatment, then I believe it is simply false to say that 'every life is of equal value.'[314]

[312] Rawls J., (1921) *A Theory of Justice*, Harvard University Press, Cambridge, Massachusetts, p163.
[313] Harris, J., (1985) *The Value of Life: An Introduction to Medical Ethics*, Routledge, London, p89.
[314] McCormick, R., (2002) The Quality of Life, the Sanctity of Life in *Theological Issues in Bioethics an Introduction with Readings*, Messer, N., (ed.), Darton, Longman & Todd, London, pp39-43.

Unjust discrimination is avoided if decision-making centres on the benefit *to the patient*, even if that benefit is described largely in terms of quality-of-life criteria, such criteria however would mean far more than the QALY measurement could ever account for. Issues of justice arise in at least two distinct contexts in donation. On the one hand, concerns arise that those who are most likely to donate organs may be the least likely to benefit from access to the services of which the donation is part. On a global scale it can lead to inhabitants of lower income countries becoming the main source of organ donors for those who live in wealthier nations. On this point, Jacquineau Azétsop and Stuart Rennie make a powerful comment that the challenge facing bioethics in resource poor settings is not to mislead people with unrealistic promises of autonomy that very few people can indeed achieve, but to 'articulate moral principles and societal values that are oriented around the promotion of equitable access to care and which broaden the goals of medicine and public health.'[315]

Should organs go to alcoholics or diabetics or obese persons for example? Should lifestyle choices dictate the opportunity for transplantation in circumstances where the potential for needing an organ is increased? Would some degree of lower priority be accorded to those who do not look after their health? Should those requiring further transplant be given less priority on the grounds of 'no-one should get seconds until the others have had firsts' particularly since second time recipients have been shown to fare less well. Should those who agree to donate be afforded the opportunity to go to the top of the transplant list if need be? Such questions are symptomatic of the range and magnitude of the problem of fairness and the necessity for a level of deliberation that extends far beyond the notion of the body as a mere physical entity.

Fairness of distribution furthermore calls into question the practice of socially directed organ donation, which could be considered a different form of discrimination. As Price points out those committed to the principle of justice would insist that the pattern of allocation is morally critical. For example would a directed donation be restricted to going first to children, or would a request that an organ go to a person of a particular race or gender, be acceptable? [316] Often the offer of an organ is just down to serendipity, being in the right place at the right time. Regional factors globally do come into play, with the net result that

[315] Azétsop, J., & Rennie, S., (2010) Principlism, medical individualism and health promotion in resource-poor countries: can autonomy-based bioethics promote social justice and population health? *Philosophy, Ethics and Humanities in Medicine*: **2010:5:1**
[316] Price, D., (2009) pp276-281

there is an exponential increase in transplant tourism within and across jurisdictions. This is a difficult matter since globally different jurisdictions have non-comparable laws and the standard and sometimes cost of healthcare is variable.

Perhaps the answer to this seemingly intractable dilemma is to choose a method of random selection as Paul Ramsay proposes:

> When the ultimate of life is the value at stake, and when not all lives can be saved, it can be reasonably argued that we should stand aside as far as possible from the choice of who shall live and who shall die. The equal right of every human being to live and not relative personal or social worth should be the ruling principle. Thus random selection is preferable not simply because life is a value incommensurate with all others, and so not negotiable by bartering one person's worth against another's. It is sustained also because we have no way of knowing how really and truly to estimate a person's societal worth or his worth to others or to himself in unfocused social situations in the ordinary lives of humankind in their communities.[317]

There is no doubt that justice as fairness in the matter of organ distribution and transfer is no inconsequential principle, the concept brings to light manifold issues that reach into the core of some very real personal and wider social concerns. The Lancet comments that there are many frameworks within which organ transplantation can operate but at the heart of any system must be trust.[318] Dying patients need to trust their families that their wishes to donate will be honoured, and moreover that doctors will provide the best end of life care possible. According to the Lancet, patients waiting for transplants must be able to trust in an ethical and fair organ supply based on clinical need and treated by doctors who will provide the highest standards of clinical care.[319] In short no matter how problematic the issue of fairness of distribution of organs turns out to be, valuing the person lying in the bed in front of the medical professional who is in dire need of whatever medical support is appropriate, is absolutely paramount.

The value of the body from a medical perspective

What makes human life valuable, and what makes it more valuable than other forms of life? As Jonathan Glover points out we should not regard a preference for human life as a mere

[317] Ramsay, P., (2002) A Human Lottery in Messer, N. (ed.) p198
[318] *The Lancet* (2013), Ensuring fair allocation of organs, **382:9888:181**
[319] *The Lancet* (2013), **382:9888:181**

prejudice in favour of our own species.[320] Any notion of speciesism might be considered objectionable partly because of its moral arbitrariness - we would need to give an adequate account of what in effect differentiates humankind from other creatures or forms of life.[321] But what if anything makes human life more than mere prejudice in favour of ourselves and our own kind? What is the basis of the belief and what indeed justifies it? These questions may seem excessively abstract and too difficult and controversial to be of help in solving everyday practical problems faced by health care professionals. Yet many of the day-to-day decisions taken in medical practice presuppose answers to these questions.

In the organ donation and transplantation environment the shortage of kidneys, hearts, lungs and livers render them valuable resources for both the patient and the doctor. Such scarcity influences consent methods, the distribution of resources and the notions of altruism and gift giving in particular and the very idea of how we wish the body to be seen. Sells in arguing presumed consent, believes that until opting-out legislation has been introduced the lack of organs available for those in dire need and who are dying is a 'tragic waste of life.'[322] In fact in their 2008 Report the Organ Donation Taskforce recommended that:

> All parts of the NHS must embrace organ donation as a usual, not unusual event. Local policies, constructed around national guidelines, should be put in place. Discussions about donation should be part of all end-of-life care when appropriate.[323]

The whole notion of donation being considered the 'norm' highlights the problems of using the body as a means to an end rather than an end in itself, argued by the Enlightenment philosopher Kant as a moral imperative in the sense of practical law. It is moreover of continuing importance not only in matters of consent, but also for transplant medicine generally.

In this Kant states:

> …[that man], and in general every rational being*, exists* as an end in himself, *not merely as a means* for arbitrary use by this or that will: he must in all his actions, whether they are directed to himself or to other rational beings, always be viewed *at the same time as an end*….Persons, therefore, are not merely subjective ends

[320] Glover, J., (2006) The Sanctity of Life in, *Bioethics: An Anthology*, 2nd edition, Kuhse, H., & Singer, P (eds.), Blackwell Publishing Ltd., Oxford, p271.
[321] Glover, J., (2006) p271
[322] Sells, R A., (1990) *Transplant Proceedings*: **22:931-932**
[323] The Organ Donation Taskforce (2008) *Organs for Transplant*: Recommendation 4, p36.

> whose existence as an object of our actions has a value *for us*; they are *objective ends* – that is, things whose existence is in itself an end…[324]

While the need of the clinician is to rid the body of disease by transplantation for instance, such a mechanistic approach is typical of those who see the body in a reductionist and somewhat simplistic manner. There are obvious consequences for concentrating on the body as a quasi-mechanical object capable of being 'repaired' rather like a car in order to extend life since it leaves behind the very nature of what constitutes humankind itself. Leder holds that the physician need not attend to the patient's intentionality when conceived as a physiological machine. Diagnosis and treatment seek to address 'the observed lesion, the quantified measurement far more than a person living in pain.' The patient's own experience and subjective voice thereby become inessential to the medical encounter:

> Modern medicine allows the hidden parts of the human form which cause disease and pain to be revealed by ignoring the lived body, and by revealing mechanisms and structures in the dead body. Real-time diagnosis with amazing scanning devices can deal with issues once thought to be miraculous, but still the patient is inert, an object of study, and what is subsequently uncovered will need to be revealed 'like the map of some alien territory. The patient must be introduced to their own body as though to a stranger.' In accord with such a medicine of distance, bioethics tends to offer only de-personalised norms and principles, far removed from the patient's own narrative and cleansed of all individuality.[325]

Campbell argues that we need to avoid simplistic accounts of the value of the body and its parts, in contrast to valuing humankind as people realising their good by having their wants satisfied. Is it morally impoverishing to think about the body devoid of a full account of the nature of our embodied selves? Whilst there is no moral imperative to treat the body as a sacred object, appreciation of the beauty and complexity of the world we inhabit depends totally on bodily existence and the way in which we perceive and value ourselves as human persons.[326] John Breck believes that to set sanctity of life against quality of life issues is a form of bio-idolatry since God-given life is ultimately fulfilled beyond the limits of biological existence.[327] Theologians such as Gilbert Meilaender have argued that life has a value to be preserved precisely because it makes other achievements possible.[328] For John Locke the 17th century philosopher and physician valuing is a conscious process and to value something is both to know what we value and to be conscious of our attitude towards it.[329] So what do

[324] Kant, I., (1948) pp90-91
[325] Leder, D., (1990) p147
[326] Campbell, A V., (2009) pp24-25
[327] Breck, J., (1998) *The Sacred Gift of Life*, St Vladimir's Seminary Press, Crestwood, New York, pp5-11.
[328] Meilaender, G., (2005) *Bioethics: A Primer for Christians*, 2nd Edition, William B. Eerdmans, Grand Rapids, Michigan, Ch.9.
[329] Locke, J., (1964*) An Essay Concerning Human Understanding*, book II, Ch27, Oxford University Press, London.

we mean by valuable? The list is endless, but what matters is not the content of an account, but that individuals have the capacity to give such an account in the first instance. If we allow that the value of life for each individual consists simply in those reasons, whatever they happen to be and however varied, if they want to go on living, then the nature of those reasons is irrelevant. As Harris says, all we need to know is that particular individuals have their own reasons - that they value their own lives and therefore such valuing should in some measure be honoured.[330]

Conclusions

Analysis of textual and research data has thrown up a series of questions relating to the ethical, pragmatic and technological debates concerning donation and transplantation. As a general point it is apparent from a focused attention on the multitude of discussions and debates that there are areas where ethical policy and opinion have been conflated with decisions which are merely of pragmatic concern. The notion of payment is an obvious example where outcomes have been influenced by policy that rules it out completely, whereas payment for any good or service is an accepted part of our everyday existence. The problem lies not in the concept itself, or in any agreement over whether payment is appropriate, but in how the discussion is played out in terms of fully examining the benefits and disadvantages before reaching any conclusions. Disentangling the moral from the historically or politically nuanced is critical if discussions and recommendations are to move forward with reliability and with confidence that all sides have been fully examined and debated in the interests of those who are likely to benefit from the decisions made.

More specifically however, whilst reflecting on the revolutionary nature of transplantation procedures, there remains the possibility that we might need to revise our perceptions of human existence both now and in the future. Is the future of consent to donate effectively going to be taken out of our hands? Who owns the body? What do we mean by the body? Is payment or incentive of whatever kind merely of pragmatic concern or are deeper questions such as how we view and value the body part of the problem? Can we be sure that the best possible opportunity for securing an organ is open to us when we are in dire need? And if not, crucially, what other avenues of healing are possible should I want to go on living? How are we to become more amenable to the idea potentially of a hybridised

[330] Harris, J., (1985) p89

body? These questions reach far beyond the mechanistic into the complex and thus multifaceted nature of bodily existence.

Arguably a more empathic and creative approach to bioethics focussed on the patient is paramount in order to keep pace with but more importantly offset some of the ethical presuppositions and questions which biotechnological advances have thus far presented. Any deconstruction of current ethical frameworks must deal with an account of the hermeneutics of the *complexity* of the body in the specialised setting of transplantation medicine. Complexity in this domain needs to be treated as a thick concept embracing not only the pragmatic and technological, critical for both ethical policy and decision-making, but more importantly for notions of selfhood as affected by ill-health.[331] The notion of the wholistic nature of the body in both health and illness has wide-ranging implications for the development of any bioethical model - a view that will be taken up in the next chapter.

[331] A thick concept in systems thought is considered multi-layered.

Chapter 5

Principlism and Alternative Bioethical Models

I am not a mechanism, an assembly of various sections.
And it is not because the mechanism is working wrongly that I am ill.
I am ill because of wounds to the soul, to the deep emotional self
and the wounds to the soul take a long, long time, only time can help
and patience, and a certain difficult repentance
long, difficult repentance, realisation of life's mistake,
and freeing oneself from the endless repetition of this mistake
which mankind at large has chosen to sanctify.[332]

D H Lawrence

Introduction

This chapter will consider a variety of ethical models, both current and historical, in order to give weight to my contention that most models or frameworks fail to live up to their original intention which is to offer guidance to such medical decision-making in order to provide benefit and a restoration of an improved level of health to the patient. Clinicians face considerable difficulties and dilemmas on a daily basis, not the least of which is who will receive an organ. The chapter therefore begins with some comment on how modern

[332] See www.goodreads.com/quotes/575443-i-am-not-mechanism

medicine developed, since it has had an influence on bioethical developments in general and ethical frameworks in particular. Subsequently the current, dominant ethical model 'Principlism' developed by Beauchamp and Childress will be critically reviewed. Finally some ethical alternatives to Principlism as suggested by bioethicists in the field will be discussed and the contribution of an ethics of care will be proposed as a potential ethical approach since it chimes with the arguments proposed throughout this study. A critical summary will subsequently point the way forward for the chapters that follow.

The rise of modern medicine

Modern medicine arose through the unification of two phenomena: the medical clinic and pathological anatomy. They were systematically brought together in a way that created a new approach towards the human body and its diseases. In contrast to pre-modern medicine patients were classified through an investigation based primarily not on what they told the doctor but rather on signs detected through inspection of their bodies - through touching, looking and listening. The philosopher Michel Foucault comments that this is most obviously represented in the enormous corpus of catalogues of different diseases assembled by physicians such as Thomas Sydenham who classified taxonomies of disease according to similarities and differences in the symptoms and clinical signs of the patient.[333] To this systematic, empirical approach to the diseases of living patients was linked a classification of disease from records of the dissection of deceased bodies. Thus in contrast to the 'traditional' way patients were treated, with the doctor being a 'friend', the body came to be viewed as a functional space that can be opened up for inspection by an impersonal expert. As Foucault asserts:

> To establish these signs (of disease)…is to project upon the living body a whole network of anatomo-pathological mappings: to draw the dotted outline of the future autopsy. The problem then is to bring to the surface that which is layered in depth; semiology will no longer be a *reading*, but the set of techniques that make it possible to constitute a *projective pathological anatomy*.[334]

Marie François Xavier Bichat considered the founder of modern medicine, and other eighteenth century physicians shared the conviction together with Foucault, that the linking of clinical observation to post-mortem dissection was critical. Diseases were then found in the form of morbid changes in the tissues that were thought to have given rise to signs and

[333] Foucault, M., (1973) p146
[334] Foucault, M., (1973) p162

sounds on the surface of the diseased body when the patient was still alive. Those systems according to Foucault however, left no room for the patients or doctors as human beings; they were reduced to little more than 'disturbances' in the representational system of diseases.[335]

Two historical theories exemplify the profound change that took place in the history of Western medicine. According to Svenaeus, the first - the progressive view, looked upon medical history as a series of discoveries by different individuals who challenged the theories of pre-modern medicine.[336] Whilst only placing their trust in the evidence of 'sound empirical knowledge', a massive body of thought was collated, which succeeded in toppling the old system that had been previously supported by a religious and conservative ideology. The other - Foucault's epistemic view, maintained that historical changes do not come about through the isolated inventions or discoveries by individuals that then accumulate in a progressive way, but rather depend on epistemological shifts in discourse, thus making possible new inventions and theories about individuals.[337]

Human beings did not come to occupy the centre of knowledge and the focus of the medical gaze until the modern clinic came into existence and the shift from the classical to the modern age had taken place. In the modern clinic the patient is not just a surface upon which diseases are read and classified, she is viewed as an *autonomous* subject. Jewson considered the 'medical cosmology of bedside medicine' to be essentially patient-centred.[338] The patient as an individual person and their symptoms and the account of their illness 'were the raw materials from which the pathological entities of medical theory were constructed.'[339]

Foucault however maintains that patients and doctors and their ways of coming together in the modern setting are merely *effects* of medical discourse not of praxis in the Aristotelian sense.[340] Since technology has taken over some of the routine work of the doctor, patients run the risk of being reduced to an object - a body, a case in patient records and further taxonomic evidence, in which the person consequently disappears altogether. The meeting

[335] Svenaeus, F., (2001) pp23-28
[336] Svenaeus, F., (2001) p26
[337] Foucault, M., (1971), p xiv
[338] Jewson, N D., (1975) The Disappearance of the Sick-Man from Medical Cosmology 1170-1870, *Sociology*: **10:225-244.** It is a position from which 21st century medicine has strayed.
[339] Jewson, N D., (1975) **10:225-244**
[340] The promotion of human flourishing - *eudaimonia*, and the mutual sharing of a good life through intellectual pursuit.

of whatever kind, between the doctor and the patient that in the history of medicine formed the basis of the medical encounter, is replaced by a new image: the scientist examining his object. This can prove problematic since the object - the patient - never ceases to be at the same time a person, and this potentially gives rise to problems of conflict and trust. Notwithstanding the fact that modern medical science and technology will continue to change the nature of the medical meeting, medical practice will at the same time remain *a meeting at its heart between persons*. And crucially a meeting that reflects at an ethical level all that is implied by the very nature of this encounter. The *nature* of that ethical encounter is the substantive point however.

Principlism - the dominant bioethical model

The model, known as Principlism, developed by Beauchamp and Childress is founded on traditional philosophical propositions espoused by Plato and Hippocrates, in a time frame that saw medicine as an unregulated and undeveloped practice where the patient frequently diagnosed their own malady and consulted with the doctor merely for curative relief.[341] And a visit to the doctor was clearly deemed unimportant. In the sixteenth century, visiting the doctor was an expensive matter, only open to the gentry; the remainder of the population relied on remedies of one sort or another and 'cures' for their maladies were handed down through generations. It was not until after the Second World War and the establishment of the National Health Service in the UK that medical services became freely available to all and bioethical matters became significant.[342]

Beauchamp and Childress's framework of the four principles: autonomy, beneficence, non-maleficence and justice which has proven its popularity through longevity by reason of their claim to its simplicity in ethical decision-making, has come under considerable scrutiny. The assertion that their model is based on universal morality applicable in any situation including medicine has been questioned for its lack of applicability in technically advanced and complex settings such as that of transplantation medicine.[343] Further a number of medical professionals suggest the problem of morality and any supporting bioethical frameworks based on either utilitarian or deontological principles lies in their inability to focus on the individual in 'provid[ing] an adequate account of day-to-day decision-making in medicine,'

[341] See the Introduction and Background to this study.
[342] Svenaeus, F., (2001) p19
[343] Beauchamp, T.L., & Childress, J.F., (2009) p3

and thus 'to provide any substantial guidance for medical practice.'[344] There is little doubt and research has indicated, that solving dilemmas in such advanced bioethical circumstances remains persistently problematic and reservations thus remain over the four principles approach as too basic and narrow in questions of both practical and ethical importance.

The four principles

Autonomy

Autonomy strongly depends on the free decisions of individuals, free from any form of coercion and entered into by free and informed agreement. It has long been argued that autonomy or respect for persons has tended to be the leading principle of biomedical ethics or research ethics respectively.[345] As evidenced in the literature review many criticisms have been levelled at autonomy-based bioethics over the past thirty years or so from a number of different angles: sociological, gender-based and multicultural amongst others. Herring believes what is really being claimed here is a right of 'bodily integrity' that is a right not to have something done to your body without your consent.[346]

The difficulty of autonomy as a principle arises especially in resource poor settings when as Azétsop and Rennie state:

> …[People] can barely afford the cost of care or satisfy the nutritional requirements for a good recovery, the ethics of medical encounter should be understood differently and expressed in different terms than patient choice….It would be more helpful to develop new sets of values that guide medical practice and promote patient participation in the healing relationship. [347]

The call for patient participation is not a new phenomenon. Patient movements were formed after the Second World War when people began demanding influence over the institution of medicine and levelled accusations against doctors for paternalistic behaviour. Until this point the physician had acted as a good father, according to Shorter.[348]

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[344] Komesaroff, P A., (1995) From Bioethics to Microethics: Ethical Debates and Clinical Medicine in *Troubled Bodies: Clinical Perspectives on Postmodernism, Medical Ethics and the Body*, Komesaroff, P., (ed.) Duke University Press, Durham, North Carolina, p65.
[345] See Gillon, R., (2003) Ethics needs principles – four can encompass the rest – and respect for autonomy should be 'first among equals, *J Med Ethics*: **29:5:307-312**
[346] Herring, J., (2012) p25
[347] Azétsop, J., & Rennie, S., (2010) *Philosophy, Ethics and Humanities in Medicine*: **2010:5:1**
[348] Shorter, E., (1985*) Bedside Manners: The Troubled History of Doctors and Patients*, Simon & Schuster, New York.

Once again patient power is to the fore in matters of care and concern, and evidence shows that these fundamental criteria appear to be lacking within the medical profession in the UK. In a study carried out in 2012 by the Patients' Association 80% of the circa 8000 respondents said they wanted to be more involved in their care, whilst around 39% rated their GP's communication skills at 5 out of 10 or less.[349] Additionally, proof from a response to the Care Quality Commission's Report of 2014 by the Nuffield Trust, confirmed that tensions still exist between financial performance and quality of care in which Nuffield suggests that such issues were in part responsible for the problems in the Mid-Staffordshire care scandal.[350] Such problems Nuffield consider to have been exacerbated by the freezing of funding in real terms within the NHS. Initiatives to cut funding while there is an ever-increasing demand for greater efficiencies in dealing with patients will inevitably influence decision-making when very expensive surgical procedures are being taken into consideration.

Where a patient resides, often referred to as the postcode lottery, and specialisation globally, dictate opportunities for transplant procedures. Equally those hospitals that specialise in certain types of transplant are likely to get better funding and easier access to organs than those hospitals not performing or minimally offering such treatment. Thus autonomy rubs up against justice in a powerful way. In this politically and financially driven climate how does a clinician decide between hip replacement surgery and an extremely expensive heart transplant for instance and what bearing will this have upon patient autonomy? Statistics for the UK given in Chapter 3 prove unequivocally how few heart transplants are undertaken. Clinical decisions in this circumstance demand an alternative mode of thinking. Focusing on a solution that reflects entirely on the needs of the patient who might otherwise die, might be more appropriate. For instance the use of ventricular assisted devices (VAD) are used as 'bridges to transplant', implanted only temporarily in order to sustain patients as they heal or await matching allographs. The implant of a VAD offers hope and a modicum of quality of life; or as 'destination therapy', understood from the start as a permanent implant, generally for those who have too many medical complications for them to qualify for transplant.[351]

The principle of autonomy renders problematic the contrast between how the world is perceived by those who are healthy and those who are in pain and discomfort and their

[349] Patients' Association, (2012): Primary Care Report Patients and GPs – Partners in Care? www.patients-association.org.uk/reports, accessed 24/04/2012.
[350] The Nuffield Trust, (2014) Nuffield Trust response to Care Quality Commission's annual State of Care Report.
[351] Sharp, L A., (2014) p111

respective views of that world. A sick individual is essentially dis-located from the world as they previously knew or experienced it so that their choices are limited and influenced by this change to their state on every level. Beauchamp and Childress however consider that personhood is too 'imprecise and vague' a concept to be of value in developing any framework based on morality.[352] But Gardiner points out our emotions influence how and what we see and are necessary to register and record facts with 'resonance and depth.'[353] Perception and affect however, are closely intertwined in informing our choices. Consequently emotions are not to be accepted simply as 'instinctive unmanageable reactions' but as sensitivities that inform our judgements.[354]

Some ethicists have argued for the notion of relational autonomy since the idea of absolute autonomy promotes the concept of an isolated person deciding what is in their best interests whereas in fact we have lives based on interdependent relationships. Thus rather than the question being 'what is best for me?' it morphs into: given the responsibility I have for those in relationships with me, and the responsibilities they owe me, 'what is the most appropriate course of action?' Thus relational autonomy involves the values of love, loyalty, friendship and care. Listening to the patient's choices in light of their relationships and the feelings of worry, concern for others and obligations they have, becomes paramount.[355] Just what these worries and concerns are, however, has to be established by the individual patient and oftentimes by their relatives.

Beneficence

Beneficence is the principle that medical professionals must do 'good' for their patients. They must cure any disease or injury where possible and avoid infliction of pain or harm. The principles of beneficence and non-maleficence are commonly stated in mainstream moral philosophy as kinds of obligation. Beneficence frequently connotes acts of mercy, kindness and charity. Beauchamp favours David Hume who makes motives of benevolence all-important in moral life, arguing that natural benevolence accounts in great part for the origin of morality. Thus acts of love, generosity and goodwill toward others are part of our human nature.[356] John Stuart Mill on the other hand argues that a single standard of

[352] Beauchamp, T L., & Childress, J F., (2009) pp69-71
[353] Gardiner, P A., (2003) A virtue ethics approach to moral dilemmas in medicine, *J Med Ethics*: **29:5:297-302**
[354] Gardiner, P A., (2003) **29:5:297-302**
[355] Herring, J., (2012) p202-203
[356] Hume, D., (1998) *An Enquiry concerning the Principles of Morals*, Beauchamp, T L., (ed.), Oxford University Press, Oxford.

beneficence allows us to decide objectively between what is right and what is wrong.[357] Thus the principle of utility or the 'greatest happiness for the greatest number' for Mill is contained in the principle of beneficence since actions are right in proportion to their promotion of happiness for all beings and wrong if they promote the reverse. For Kant the motive behind beneficent actions is duty.[358] However, Stanley Rudman has argued that neither of the two main types of ethical theory, utilitarianism and deontological Kantianism is adequate to resolve the problems encountered in applied ethics.[359] And without careful attention to individual context and detail, Rudman believes basic principles are insufficient. Once the practitioner embarks on a specific case, it is the context and the details that begin to matter more. Consequently contextual description is not just a matter of filling in the descriptive details of a case history.[360] Earl Winkler and Jerrold Coombs have argued that an applied ethics model 'puts the cart before the horse', because it proceeds deductively and tries to fit the case to the principles instead of starting with the situation.[361] They claim that the Principlism model is overambitious about the role of ethical justification. In fact context is often more sceptical: 'justification is essentially continuous with the case-driven inductive process of seeming the most reasonable solution to the problem.'[362]

In a healthcare setting the professional's view of both harm to and benefit for a patient can differ sharply from that of the patient and yet the professional's understanding of benefits often depends on the patient's view of what constitutes a benefit to them or indeed a worthwhile risk. Since different patients have different views about what constitutes a harm or a benefit it is therefore difficult to defend principles that are considered objectively independent of the patient's judgement.[363] Transplantation medicine is particularly testing in the matter of beneficence and non-maleficence. The fact remains that either someone has to die to donate an organ or a perfectly healthy individual becomes a patient with all the potential problems caused in carrying out an act of considerable benevolence. This includes the risk of complex surgery and anaesthesia as a prerequisite, as previously discussed.[364] An act of benevolence would accord entirely with the view of beneficence argued by Singer,

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[357] Mill, J S., (1969) *Utilitarianism* and *On Liberty*, in the *Collected Works of John Stuart Mill*, Toronto: University of Toronto Press.
[358] Kant, I., (1948) *Groundwork of the Metaphysic of Morals,* Paton, H J., (translator and analyst), Routledge, London, 52-57*ff*, pp30-31.
[359] Rudman, S., (1997) *Concepts of Person and Christian Ethics*, Cambridge University Press, Cambridge, pp229-230.
[360] Rudman, S., (1997) pp229-230
[361] Winkler, E R., & Coombs J R., (1993) *Applied Ethics: A Reader*, Blackwell, Oxford, Ch.19.
[362] Winkler, E R., & Coombs J R., (1993) Ch.19
[363] Herring, J., (2012) p29
[364] See the Introduction and Background to this study.

who advocates that those who are in a position to do so ought to make extreme sacrifice in the act of helping those in need.[365]

Both the principles of beneficence and non-maleficence may well apply under normal circumstances, since in general we are naturally predisposed to help others. The overriding issues in the case of transplantation medicine lie in using the body as an object that may well cause harm to one healthy donor for the sake paradoxically of saving the life of another very sick person whose life expectancy might in any case be curtailed. Can this be considered justifiable when for instance the live donor incurs such significant risk both to their short or potentially long-term health?[366]

Non-maleficence

At its core the principle of non-maleficence asserts that one person should not cause harm to others. For medical professionals there is a well-established principle: *Primum non nocere*, 'above all do no harm' which forms the foundation for part of the Hippocratic Oath. What does harm mean however? There is a wide-ranging understanding of harms to humanity as creatures of meaning who fundamentally can be harmed if the basic goods of life and relationship are in any way hampered. It is a complex principle that demonstrates how possible it is to have a definition of harm that goes well beyond pain. John Herring argues that the importance of non-maleficence in a medical setting 'urges against harming one patient to help another.'[367]

Harm can be variously defined particularly in cases where certain patients' views are out of step with generally accepted societal norms - the practice of euthanasia is a pertinent example. In this case disagreements arise over what 'harm' connotes. At its most rudimentary, the principle captures the notion that doctors should never use their medical training for immoral purposes. Emily Jackson argues that it is this principle that proscribes medical participation in euthanasia.[368] However, the view of life as a loan from God, may not support the traditional prohibition of suicide and euthanasia. As Hume reasoned in the eighteenth century, if artificially ending life trespasses on God's position as the giver and owner of life, the same could be said about artificially prolonging someone's life by giving

[365] Singer, P., (1972) Famine, Affluence and Morality, *Philosophy and Public Affairs*: **1:3:229-243**
[366] For kidney donors, the likelihood of their need for a transplant of their remaining kidney increases.
[367] Herring, J., (2012) p26
[368] Jackson, E., (2010) *Medical Law, Text, Cases and Materials*, 2nd edition Oxford University Press, Oxford, p15.

life-saving medical treatment.[369] Should a doctor agree to a request for euthanasia, it could be concluded that the patient has not been harmed, but rather that the doctor has acted to avoid the greater harm of a protracted and distressing death. Arguments for various kinds of utilitarian approach suggest that allowing assisted suicide and euthanasia would result in more benefit and less harm than continuing to prohibit it. What is more Peter Singer maintains that in decision-making, the preferences of all concerned should be satisfied.[370] Whilst there are guidelines from a variety of sources such as NICE and the BMA, what counts as a harm is determined also by the individual, thus echoing in some sense the principle of autonomy.[371] If a person has consented to organ donation for instance and the doctor provides the necessary procedure, the non-maleficence principle is not infringed. In this case, it is informed consent under the criterion of autonomy that becomes crucial, as it gives important assurance to both parties that medical intervention is approved no matter what that intervention might portend.[372]

The principle of non-maleficence if taken too literally is nonsensical. Most medical treatments of whatever sort involve the causing of some harm even if it is just an injection. Whilst non-maleficence raises some very thorny questions and thereby has to strike a delicate balance between moral, societal and individual acceptability, when seen as a whole however, the principle maintains that medical intervention should not cause harm, and as previously noted this appears to function similarly to the principle of beneficence.

Justice

Justice is often interpreted legally to mean that we should treat like cases alike. This depends on being able to tell when medical cases are either 'like' or 'unlike'. So when allocating lungs for transplant for example, are we acting justly by making smokers a lower priority than non-smokers (unlike) or should the only relevant decision be based on clinical need, in which case the two instances are like? It is seldom possible to give every patient immediate access to the best medical treatment so the rationing of scarce resources must be fair and transparent.

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[369] Hume, D., (1882) Of Suicide, in *Philosophical Works*, vol.4, Green, T H., & Grose, T H., (eds.), Longman Green, London, reprinted (1964) Scientia Verlag, Aalen, pp406-14.
[370] Kuhse, H., & Singer, P., (2006), pp1-9
[371] Autonomy is an important part of Kant's moral theory, since for him autonomy does not mean permission to act completely individualistically. In arguments over euthanasia, however it may be that utilitarian concepts are in play here. In the sense that people should have the freedom to direct their lives as they see fit, so long as their choices do not interfere with the freedom of others.
[372] Including tissue sampling that may be stored and used for further education and research.

In medical cases Ivan Illich argues that the meting out of justice lies entirely in the hands of the physicians.[373] Courts of law, when not strictly enforcing legal adherence in matters medical, are powerless in comparison with the physician. In commenting on the authority of the doctor, Illich suggests that only doctors know what constitutes sickness, who is sick, what should be done to the sick and to those who are considered to be at special risk. For him the doctor is the ultimate arbiter and the breakdown between medicine and morality has been defended on the grounds that medical categories rest on scientific foundations exempt from moral evaluation.

The fair distribution of organs is problematic for a variety of reasons, as discussed in Chapter 4. Whilst Illich's presuppositions may well be considered rather harsh and extreme, justice in this area of medicine rests on several factors including the results of tests such as risk assessment and quality of life criteria, which might arguably sit more comfortably in a business milieu.[374] In confirmation of Illich's view, Manson and O'Neill believe, that the principle of justice sits rather uncomfortably within the Principlist framework. They maintain that it needs expansion into acknowledgement of sociocultural factors that have direct influence on the welfare and happiness of those patients who are involved in the transplantation process.[375] I believe that an ethical response should include an appreciation of the quality of the patient's needs in life, together with what value really means in this context for them. We would have to question Illich's assumptions that the doctor is the sole arbiter, since the value of any patient's life I believe unequivocally should take into account individual patient input.

Does universal morality exist?

The four principle framework was originally established as a basic ethic which Beauchamp and Childress defend as a set of moral principles to function as 'general norms of the common morality that are a suitable starting point for biomedical ethics.'[376] Lively comment over their claim to universality has been articulated, critics such as Søren Holm believe that the culture in which the Principlist model was developed is too specific to be considered

[373] Illich, I., (2013) *Limits to Medicine: Medical Nemesis: The Expropriation of Health*, Marion Boyers, London, p47.
[374] Cost-benefit analysis, risk analysis and QALYs (quality-adjusted life years). See Ch.4 of this study.
[375] See Manson, N C., & O'Neil, O., in Ch.4 of this study.
[376] Beauchamp, T L., & Childress, J F., (2013) p12

universal.[377] Tom Walker sees Principlism as problematic: firstly more than four principles are needed to capture morality in general; secondly if Principlism is taken to be an attempt to capture universalisable moral norms, such an account rules out much of what we take to be morally significant.[378] In fact Walker goes on to argue that those who advocate Principlism 'owe us an explanation of why morality is so narrowly constrained', and suggests that a move toward a culture-specific version which would contain more than four principles might provide a more acceptable solution.[379]

Gillon and Ruth Macklin support the Principlist framework as it stands. Gillon agrees that the four principles are a very good way of dealing with problems of healthcare as they 'permit a thorough and systematic analysis of real bioethical problems.'[380] And Macklin goes so far as to state:

> No wonder that so many practising health professions clutch with relief at the four principles which provide a familiar moral language and seem to encompass everything. Part of the attraction must be the implication that a mere four factors need to be considered but for this to be the case, a certain elasticity of definition is required. In fact on analysis it seems that the four principles eventually come to include all the values, guidelines, codes and legislation that one can imagine.[381]

Joan McCarthy considers the four principles to provide a method of supporting ethical decisions that have a 'strong justificatory force.' [382] That is the force of the imperative to 'tell the truth' derives from grounding in universally accepted norms, not from a subjective viewpoint or the intuition of the health professional. She believes furthermore that the processes of moral deliberation are akin to scientific processes since they involve 'the setting up of hypotheses that are tested and modified or rejected on the basis of reasoning and experience.'[383] Thus in situations involving doubt and uncertainty, the deliberative process which comes into play appeals to reasoning strategies and goals that are also considered

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[377] Søren Holm wrote an article in 1995 entitled 'Not just Autonomy – the Principles of American Biomedical Ethics' in which he questions whether the model expresses a typical American view. Equally Rendtorff and Kemp published 'Basic ethical principles in European bioethics and biolaw' in 2000 concluding that the model is too narrowly focussed on the American culture, and offering a wider perspective including dignity, integrity and vulnerability which they claim to be a more expansive view of the human person. Moreover East Asian bioethicists have questioned Beauchamp and Childress' universal theory believing there is some difference between East and West in relation to the principle of autonomy.

[378] Walker, T., (2009) What Principlism misses, *J Med Ethics*: **35:4:229-231**

[379] Walker, T., (2009) **35:4:229-231**

[380] Gillon, R., (2003) Ethics needs principles - four can encompass the rest – and respect for autonomy should be 'first among equals, *J Med Ethics*: **29:5:307-312**

[381] Macklin, R., (2003) Applying the four principles, *J Med Ethics*: **29:5:275-280**

[382] McCarthy, J., (2003) Principlism or narrative ethics: must we choose between them? *Med Humanities*: **29:5:65-71**

[383] McCarthy, J., (2003) **29:5:65-71**

objective, not intuitive. In suggesting however that the Principlist approach would be considerably strengthened by narrative ethics which has its roots in literature and philosophy, McCarthy continues by saying that: 'The strength of narrative ethics…is that it provides a method and vocabulary for interpreting and respecting the unique and personal stories of individuals. On this view, any decision about medical treatment or health care must be considered in the light of the person's individual story or stories.'[384] Much as I would concur, McCarthy's proposition would appear to run counter to Beauchamp and Childress's fundamental premise that issues of a subjective nature are inappropriate in development of a bioethical model because they are too diverse and hence unstable to be credited with moral status.[385] However I agree with her premise.

Whilst Beauchamp and Childress declare their principles to have some universal appeal in functioning as 'general guidelines for the formulation of the more specific rules',[386] it is not entirely clear how their model might be 'adapted' in such specific cases as dilemmas resulting from issues within transplantation medicine. Issues that might well sit outside the four principles framework, for example those of a sensitive, personal nature, involving some kind of recompense for donating an organ. Nor is it obvious how some universal morality would operate under such special circumstances given the diversity of either religious or socio-cultural norms and values that are held by different nations. For instance, the Japanese religion Shinto believes the body to be impure after death and interfering with a corpse is said to bring bad luck; Jehovah's Witnesses do not encourage organ donation and religions such as Buddhism and Hinduism leave it up to individual conscience, although some believe the act to be both charitable and compassionate.[387]

According to Mike Burley, in the case of Hindu beliefs and culture views exist that may determine the choice for donation, for example the act of selfless giving - *daan* is virtuous, including aspects of generosity, charity and sharing with others.[388] And Flood argues, the importance for Hindu soteriology is freedom from the cycle of rebirth exercised through karmic accumulation, through for instance acts of selflessness. Karmic benefit is accrued through both leading a 'good' life and preparing the way for a 'good' death.' [389]

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[384] McCarthy, J., (2003) **29:5:65-71**
[385] Beauchamp, T L., & Childress, J F., (2013) p68
[386] Beauchamp, T L., & Childress, J F., (2013) p13
[387] See www.bbc.co.uk/religion/religions/shinto/shintoethics/organs.html
[388] Burley M., (2000) *Hatha Yoga: Its Context, Theory and Practice*, Motilal Banarsidas, India, pp190-191.
[389] Flood, G., (1996) pp85-86

Acts of compassion and charity are perceived as adding to the store of karma built up through the lifetime of the individual in order to ensure a 'smooth' and unencumbered passage into the next life. Thus organ donation is sanctioned, considered as a charitable act so long as the body is treated with respect.

Certain Hindu traditions also consider donation from a wholistic perspective where bodily integrity post mortem is paramount and the passage of the soul after death becomes critical. Strict adherence to the rituals for the deceased is prescriptive. The body must be treated according to ceremonial rites of passage, to aid transmigration. Prayers are offered and further rituals are enacted, but at no time is the body either to be embalmed or organs to be removed. In this manner bodily integrity is maintained.[390] In such a case ritual practices may act against any form of donation. For many Buddhists the final moment of consciousness is the most important of all. Family members are not supposed to touch the corpse for three to eight hours after breathing ceases. Thus preparation for the performance of religious ceremonies after death takes place is deferred for some period. Buddhists believe that the spirit of a person will linger on for some time and can be affected by what has happened to the corpse. It is important that the body is treated gently and with respect so that the spirit can continue its journey calmly and in a state of grace.[391]

Cultural norms and mores are of obvious importance when the question of deceased donation is mooted. Whilst claims are made by NHSBT in their organ donation pamphlets that it is up to the individual to make the decision to donate, this is far too generalist.[392] Given such cultural diversity within Hindu and Buddhist values and traditions, it could be insensitive to broach the subject to those whose religious beliefs would override any idea of donating an organ at the time or even approaching the time of death. Furthermore this renders problematic any notion of legalising presumed consent.

In halting any concept of universalism, Heyward argues that the need for ethics arises whenever, on the basis of our values, we are pulled between conflicting obligations or moral claims. For her ethics originates in the complex relationship of needs, values, obligations and visions.[393] This realisation pushes us to think ethically, not on the basis of who we are in and of ourselves, but rather of who we are together in the world, our work, our colleagues and

[390] Hinduism Today: Death and Dying www.hinduismtoday.com accessed 15/03/2016.
[391] Thich Nguyen Tang, Buddhist Views on Death and Rebirth, http//www.urbandharma.org accessed 16/03/2016.
[392] See the NHSBT website, www.nhsbt.nhs.uk
[393] Heyward, C., (1989) pp124-125

our relationships, which involves becoming radically aware of our selves in relation. The affirmation of ourselves together allows us to envision guidelines for morality in a confidence that our differences need not break our body. 'We are one body with many members. We are not alike in our cultures, credos, experiences, desires - we need to respect our differences.'[394] The issue appears to be one of the difference between an ethic which sits above what might be called the common morality and the everyday dilemmas encountered by doctors that effect and are affected by what is considered good for the patient and their own desires and concerns.

It also seems to be the case that a pre-occupation with normative codes of conduct in general hampers research. Sharp maintains that biomedicine on all levels is hemmed in by the 'strident set of four principles.' Interestingly in her anthropological research she notes with some surprise the

> …[Ubiquitous] application of the four bioethical principles to science based research not only in the United States but also in Canada, the United Kingdom, New Zealand and Australia…In other words, bioethics (at least in the guise of the model originally espoused by Beauchamp and Childress) is now pervasive, referencing codified and thus standardized or established categories that dictate moral conduct in the laboratory and beyond.[395]

In her account Sharp reveals that in fact many research scientists proved to be well versed in the framework reporting that the Principlist approach underpins and puts shape to the rigorous requirements of grant applications within private foundations together with online training and certification programmes in universities in the USA.[396] We might question whether Beauchamp and Childress's model is being used under these circumstances as a protocol to achieve some end that sits completely outside of the domain of its original ethical intentions.

An overview of alternative bioethical approaches

Doubts remain over the Principlist model in its entirety whether they are over its universalisability, its internal consistency and cohesiveness, or even the breadth of bioethical concerns it encompasses. As arguments have demonstrated, importance on the manner in which the body is perceived influences bioethically what is needed to support medical and

[394] Heyward, C., (1989) pp124-125
[395] Sharp, L A., (2014) p35
[396] Sharp, L A., (2014) p35

research procedures. Chapter 2 outlining alternative views of the body, shows the standard model of western medicine as wanting. Thus ignoring embodied being and its particularity, means that ethical frameworks developed on utilitarian or even deontological lines leave aside the individual and their perceptions of what is of benefit to them.

After much criticism from other bioethicists of the Principlist framework, Beauchamp and Childress minimally added certain character traits from Virtue Ethics to their original four criteria. Whilst proposing that Virtue Ethics has value in specific circumstances such as caring in hospitals or truthfulness in research, they draw a distinction between ethical guidelines that govern overall practice, and professional roles in biomedical fields that are 'usually tied to institutional expectations and standards of professional practice.'[397] Unfortunately, bioethical alternatives or the inclusion of some of their criteria, appear equally as problematic as the Principlist framework, since they are incompatible with the basic premises in Beauchamp and Childress's model, and incompatible with each other.

Daniel Callahan favours a communitarian framework that entails focussing on the social meaning, implications and context of any given ethical issue as a way of thinking about ethical problems, rather than providing any rigid criteria for dealing with them.[398] Communitarianism assumes that humans are socially inclined beings whose lives are lived out within 'deeply penetrating social, political and cultural institutions.'[399] Callahan's approach rests on analytical skills and personal virtues. It emphasises that living in a decent community and society is key to a good life. When we consider an issue such as whether a person should be allowed to sell their kidneys, the communitarian approach would be to ask whether kidney selling is compatible with a decent society. Critics of this approach might point out that a decent society is one that respects individuals' rights rather than a society's willingness to interfere with those rights for the greater good. Utilitarian approaches have in general been criticised for promoting the interests of the community above the interests of those individuals on the margins of society who may be its most vulnerable members.

Paul Gardiner advocates a virtue ethics approach. Virtue ethics emphasises that it is attitudes motivating action in assessing the morally right thing to do rather than the

[397] Beauchamp, T L., & Childress, J F., (2013) pp32-33
[398] Callahan, D., (2003) Principlism and Communitarianism, in *The Journal of Medical Ethics*: **29:5:287-291**
[399] Callahan, D., (2003)**: 29:5:287-291**

consequences of those actions that matter.[400] Thus character is the determining factor within any dominant ethos. The four cardinal virtues advocated by Socrates and Aristotle: prudence, temperance, justice and fortitude or courage are well known. Virtues, essentially good habits, direct human nature toward good actions. However, those who favour a virtue approach disagree over the extent to which consequences can be used to assess the appropriateness of an act. In a healthcare context qualities of compassion, honesty, fairness and diligence are those we demand and have come to expect.[401] Beauchamp and Childress have added five focal virtues to their four principles: compassion, discernment, trustworthiness, integrity and conscientiousness.[402] They claim that these additions provide 'a moral compass of character for health professionals' as they are 'important in part for the development and expression of caring.'[403] Two questions arise however. Firstly how do these additions fit in with their model, where the original four principles already either sit uncomfortably with each other or are considered superfluous? Secondly Beauchamp and Childress argue that those additions would be intrinsic to the practice of any doctor who astutely follows their basic four principles in any case. It seems that such adjuncts could be seen as a mere sop to the comments from their critics.

Notwithstanding, a basic concern of the virtue approach rests in deciding exactly which virtues are critical. In such a diverse society agreement over what a virtuous person is will remain contentious. Although virtue ethics might provide an expectation that medical professionals act appropriately, as a framework for practical guidance in such ethical dilemmas as the fairness of healthcare rationing for instance, is problematic. Basing decisions on virtues will prove an issue fundamentally because a broader perspective is required when complex decisions arise - for example whether to offer a heart transplant to an elderly person when many other less expensive procedures could be performed in its stead. Fairness is an ambiguous concept, as I discussed in Chapter 4 since it sits beyond the remit of the individual medical professional who has limited control over what counts as a virtuous/valuable life and moreover limited control over the allocation of financial resources. In particular over any decision to undertake extremely expensive transplant procedures in a regional area whose finances are already stretched even in provision of less intricate surgical interventions.

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[400] Gardiner, P., (2003) A virtue ethics approach to moral dilemmas in medicine in *The Journal of Medical Ethics*: **29:5:297-302**

[401] Herring, J., (2012*)* pp33-34

[402] As additional specifications to the model of four principles, Beauchamp, T L., & Childress, J F., (2013) p379-384

[403] Beauchamp, T L., & Childress, J F., (2013) Ch.2.

Somewhat akin to Callahan, but focused rather on the individual within a community, Arthur Frank suggests a multi-vocal ethic. When the body's vulnerability and pain are kept in the foreground as an important part of what it is to be human, he believes a multi-vocal ethic which is in no way suggestive of universalism, would underpin 'a new social ethic.'[404] The challenge is to state this ethic in terms that remain multi-vocal; it implies the need to recognise multiple voices and to afford each its 'full legitimacy in reaching a consensus that is not only workable in achieving compliance of all parties, but is also moral in the sense of respecting the values of all those whose compliance is required.'[405] What would be helpful in clinical ethics is not a replacement of existing positions, but a shift towards a multi-vocality that balances out the views of all involved, by making each aware of the other. Frank argues that in a multi-vocal medical environment, it is vital that non-medical voices should be heard too. Given the limitations of informed consent as discussed in Chapter 3, whilst a plurality of voices may be difficult to manage because of resource constraints within the NHS across the board, gathering those voices is nonetheless possible through support groups for instance. That healing requires an approach that includes the opportunity for the patient to have greater input into their treatment is an issue discussed throughout this study. And whilst multi-vocality may be once more a partial solution it goes some way towards a more fluid, wholistic and caring approach to healing that affords an efficacious and improved long-term outcome for the patient - a theme I shall be taking up in Chapter 6.

Care ethics

The concepts in care ethics appear to echo more closely the wholistic and relational interpretation of the body and its needs emphasised by this study.[406] Care ethics is one of a cluster of normative ethical theories that were developed by feminists in the second half of the twentieth century. It was Carol Gilligan the psychologist, in her seminal work *In a Different Voice* written in 1982, who established a way forward for an ethics of care. In concluding that the way people talk about their lives is significant, that the language they use and the connections they make is revelatory, Gilligan believes the world they see and in which they act is disclosed.[407] From her perspective identity formation and moral development in women's adolescence and adulthood are key to understanding an ethics of care. She maintains that a responsibility to discern and alleviate suffering which takes place

[404] Frank, A W., (2013) *The Wounded Storyteller: Body, Illness & Ethics*, 2nd edition, University of Chicago Press, Chicago, pp146-147.
[405] Frank, A W., (2013) p147
[406] See Ch.7 in this study.
[407] Gilligan, C., (1982) *In a Different Voice*, Harvard University Press, Cambridge, Massachusetts, pp2-3.

through an understanding of the psychological reasoning within mother and child relationships, ultimately leads to an emphasis on everyone's need for care.[408]

According to Gilligan, women impose a distinctive construction on moral problems, seeing moral dilemmas in terms of conflicting responsibilities. The sequence of women's moral judgement proceeds from an initial concern with survival to a focus on goodness and finally to a reflective understanding of the resolution of conflict in human relationships. The concepts of responsibility and care in women's constructions of the moral domain, the close tie in women's thinking between conceptions of self and of morality, are key to Gilligan's assumptions. In their portrayal of relationships, she considers that women replace the bias of men toward separation with a representation of the interdependence of self and other, both in love and work.[409] By changing the emphasis from individual achievement to relationships of care, there is an ensuing shift towards the progress of relationality. Life transitions seem to involve women in a distinctive way. For instance when the distinction between helping and pleasing frees the activity of taking care from the wish for approval by others, the ethic of responsibility results in the growth of personal integrity and strength - post-menopausal women have in the past been referred to as crones for their wisdom and considerable experience of nurturing for example. By contrast, Gilligan argues that the moral imperative for men appears to be restricted to respecting the rights of others, including protection from interference to the rights to life and self-fulfilment, which pivots on turning attention away from the logic of care to the consequence of choice.[410] For women the integration of rights and responsibilities takes place through a psychological logic of relationships. Gilligan holds that men come to see the limitations of a conception of justice blinded to the differences in human life whilst women come to see the violence inherent in inequality.

Gilligan puts forward a gender specific argument such that the moral imperative for women lies in the responsibility to care which she maintains paradoxically is relational.[411] Her views whilst being praised when first published, have received notable criticism for their narrowness of perspective. For instance, Lawrence Kohlberg[412] and Jürgen Habermas[413] maintain that Gilligan's research on the ethics of care is not about moral theory at all. In

[408] Gilligan, C., (1982) p100
[409] Gilligan, C., (1982) p170
[410] Gilligan, C., (1982) p100
[411] Gilligan, C., (1982) pp171-2
[412] Kohlberg, L., (1984) Essays on Moral Development, vol.2, Harper and Row, San Francisco, pp340-341.
[413] Habermas, J., (1990) *The Theory of Communicative Action,* vol.1*: Reason and the Rationalization of Society*, Beacon Press, Boston.

supporting Principlist ethics they argue that her theory is about evaluations of virtue and character in personal relationships, about the good life - but not about moral theory. They maintain, by contrast that moral theory concerns justice and the shape it should take in society. Principlist bioethics from their perspective is unequivocally about justice because it involves the application of universal principles to broad social issues, such as equal access to health care and professional training, the allocation of scarce medical resources and policies on controversial medical issues such as abortion and euthanasia. In contrast, Christine Gudorf endorses a position that morality concerns the question of what may be considered truly human. True humanity is not defined solely by moral principles such as justice, or even patient autonomy but by all the ways in which we care for the other, ourselves and our world.[414]

For Maria Puig de la Bellacasa controversy surrounding the origins of caring's ethical subjectivity in the mother and child relation has resulted in discussions being expanded and challenged from a range of perspectives that reach well beyond activities traditionally identified as women's work.[415] The ethics of care has moved on. Concepts of care have been put to the test and explored critically through psychology (Nel Noddings), political theory (Joan Tronto), justice (Daniel Engster), anthropologies of health work and sciences (Anne Marie Mol, Ingunn Moser and Jeannette Pols) besides many more that cut across every facet of existence.[416] These engagements with care make specific contributions to care's breadth and meaning, revealing how caring implicates different relationalities, issues and practices in diverse settings. De la Bellacasa however sees care, caring and carer as contested words.[417] Most of us need care, feel care, are cared for or encounter care, in one way or another. Care is omnipresent even through the effects of its absence. Care passes within, across and throughout things. But its lack unravels. To care can feel good, but it can also feel awful. It can do good but it can also oppress in the sense that it can convey control.[418] In a controlling environment, care can be ambivalent in significance as well as ontology.[419]

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[414] Gudorf, C., (2001) The Need for Integrating Care Ethics into Hospital Care: A Case Study in Cates, D F., and Lauritzen, P., (eds.) *Medicine and the Ethics of Care*, Georgetown University Press, Washington, p72.
[415] De la Bellacasa, M P., (2017) *Matters of Care*, University of Minnesota Press, Minneapolis, pp2-3.
[416] Noddings, N., (1984) *Caring, a Feminine Approach to Ethics and Moral Education*, University of California Press, Berkeley; Tronto, J., (1993) *Moral Boundaries: A Political Argument for an Ethic of Care*, Routlege, New York; Engster, D., (2009) *The Heart of Justice: Care Ethics and Political Theory*, Oxford University Press, Oxford; Mol, A-M., Moser, I., & Pols, J., (2010) (eds.) *Care in Practice: On Tinkering in Clinics, Homes and Farms*, Transcript, Bielefeld.
[417] De la Bellacasa, M P., (2017) p1
[418] See Mol and Allmark below.
[419] De la Bellacasa, M P., (2017) p2

In contrast, care includes *everything that we do* to maintain, continue and repair our world so that we can live in it as well as possible according Tronto. That world includes our bodies, our selves and our environment, 'all of which we seek to interweave in a complex, life-sustaining web.'[420] An integrated act of care considers affective and ethical outlooks involved in concern, worry and taking responsibility for other's wellbeing, such 'as caring about' and 'taking care of' that need to be supported by material practices such as care-giving and care-receiving.[421] In contrast to Gilligan, de la Bellacasa argues that such a distinction does not separate these modes of agency, but allows us to emphasise the notion that a politics of care engages much more than a moral stance. 'It involves affective, ethical, hands-on agencies of practical and material consequence, as well as an accent on care as a vital interconnection with the web of life.'[422] It also suggests interdependency as the ontological state in which humans and countless other beings unavoidably live.

Tensions exist within the diverse range of care's broader remit. Care can be a burden, a joy or simply boring. Besides committing to the work of love, care can turn into moral pressure for workers. These tensions expose that vital maintenance is not sufficient for a relation to involve care, but without maintenance work, affectivity remains closer to moral intention, to a disposition 'to care about' without putting in the work to 'care for.'[423] This similarly applies to ethical and political questions raised by care, such as condemnation about its absence, or about controlling policies that regulate what is considered legitimate care.

Mol discusses the notion of care in medical practices: '[a]rticulating good care …is an intervention' rather than a factual evaluation or judgement of practice.[424] Care is never neutral: it can be carried out in contexts within and for settings that we might find objectionable. Calls for caring though are everywhere. People are summoned to care for everything but foremost for 'ourselves', our lifestyle, our bodies, our physical and mental fitness or that of our families, reducing care to its most 'parochial caricature.'[425] Nurses are constantly criticised for not caring enough, or not caring anymore, or for having lost some

[420] Tronto J., (1993) p103
[421] Tronto J., (1993) pp105-108
[422] De la Bellacasa, M P., (2017) p5
[423] Tronto J., (1993) pp105-108
[424] Mol, A-M., (2008) *The Logic of Care: Health and the Problem of Patient Choice*, Routledge, New York, p84.
[425] Tronto J., (1993) pp105-108

natural capacity to care, while pay and conditions worsen in the NHS year on year and time and space to carry out their tasks is at a premium.[426]

The ethics of care approach, inevitably has received its fair share of criticism in other ways.[427] It has been argued by feminists that its glorification of caring and dependency is likely to be harmful to women since the role of women as carers and dependants according to Wolf et al, has led to their oppression and subordination.[428] Some concern centres on the notion of care itself as being too vague. Peter Allmark rightly points out that not all caring relationships could be considered good; they may involve manipulation and domination.[429] I would see the promotion of the values of care as being context dependent and therefore as remaining fluid, rather than static in any relationship, be that medical or otherwise. Care in an intensive unit is manifestly different from that required in stitching a wound in the emergency department, although it must be said that the skills are equally critical and the doctors will be 'doing their best' for the patient according to beneficent principles.[430] The issue is whether care, that turns out to be manipulative, is really care at all. Surely manipulation is more concerned with issues of power, control and authority rather than with care. Caring is about being present to both ourselves and importantly to the other, an acute awareness of each other's needs for love.[431]

Conclusions

Midgley points out that during the twentieth century: 'the quarantining of morality from topics that obviously relate to it' has led to a position where morality is seen as 'something vague, irrational, privatized, inarticulate and subjective - in fact as something beautiful but trivial.'[432] She claims that ethics has been shut off from the rest of 'the intellectual scene' and 'shares company with a number of other topics' which 'are awkward items including

[426] Lara Rachel Cohen offers a radical critique of how the promotion of 'compassionate care' in this context diverts attention away from the 'body-work' involved in nursing relations of care. Cohen, R., (2011) Time, Space and Touch at Work: Body Work and Labour Process (Re)Organisation, in *Sociology of Health & Illness*: **33:2:189-205**

[427] Herring, J., (2012*)* p33

[428] Wolf, S., (1996) (ed.) Introduction: gender and feminism in bioethics, in *Feminism and Bioethics*, Oxford University Press, Oxford, p9. See also Heyward, C., (1989), and Irigaray, L., (1985).

[429] Allmark, P., (2002) Can there be an ethics of care? in *Healthcare Ethics and Human Values*, Fulford, K., Dickenson, D., & Murray, T., (eds.), Blackwell, Oxford.

[430] As in adhering to the criteria of beneficence and non-maleficence, but also to their own rationale for becoming a doctor in the first place.

[431] Schneider, L., (2008) pp199-209

[432] Midgley, M., (1994) p14

consciousness, emotion, creativity and free will', resulting from the transformation historically of patient-centred medicine to a science-based practice.[433]

Ethics, as has been frequently remarked, is certainly not an exact science. The need for bioethics to be dynamic is pressing, reflecting the fast-moving pace of biotechnology. To keep pace any bioethical framework has to be capable of revision to reflect current trends including advanced surgical and biotechnical developments. Research from this study has shown that piecemeal suggestions put forward have resulted in very little movement towards the creation of an ethical response that addresses the enormity of biotechnological advancement and its influence on complicated medical procedures. Indeed Beauchamp and Childress's book which proposes the four principles approach, despite being in its 7th edition has fundamentally not changed for some forty years, and this lack of development has wide-ranging implications for policy-making in particular and more importantly for recommendations to changes in the law both now and in the future as biotechnology increases in everyday use within patients' households.[434]

According to Sharp, the Principlist framework seems to underpin an ethic far more suited to particular research practitioners who are required to satisfy the relevant authorities that a certain protocol has been followed before proceeding with medical research and the resulting medical input.[435] A 'simplified' ethic that fulfils a 'tick-in-the-box' exercise appears to be both attractive and meets the legal requirement. In an era of increasing litigation the fact that the accepted protocol has been followed is absolutely imperative to avoid any problems should 'things go awry.' Essential to any exploration involved in creating an ethical approach that focuses to a greater degree on such affective factors as those proposed in Chapter 2, the patient is absolutely central to any medical involvement or intervention as this is vital for their own healing; a healing marked also by the re-establishment of their innate power and connection to all that exists.

Acknowledgement of the importance of affective and sociocultural factors is surely critical. Questions remain as to why the body is considered as anything other than an object in the context of transplantation, useful in supplying parts to those in dire need in order to save their lives.[436] What is it that distinguishes humanity from other forms of life? What value do

[433] Midgley, M., (1994) p14
[434] A point I shall be returning to in Chapter 8.
[435] Sharp, L A., (2014) p5
[436] See the quotation by Sells at the beginning of the Introduction and Background to this study.

we extend to the human being and how will that value be transformed in an age where hybridisation becomes an increasing possibility? Have we reached a point therefore in such fast-pace technical advancement where we need to rethink what constitutes human being? I believe we might have. Chapter 8 argues this very possibility.

Too frequently in a medical encounter the patient remains effectively a silent witness to their own dis-ease. Exacerbated by both medical language and highly sophisticated medical procedures, patient alienation is problematic. Leder in '*The Absent Body'* asks 'why, if human experience is rooted in the bodily, is the body so often absent from experience?' [437] As he suggests, the healthy body is primarily directed towards intimately connecting within the world as a normal and taken-for-granted position in direct contrast to the body experiencing illness:

> In the case of health, the body is alien by virtue of its disappearance, as attention is primarily directed toward the world. With the onset of illness this gives way to dys-appearance. The body is no longer alien-as-forgotten, but precisely as remembered, a sharp and searing presence threatening the self. One is a mode of silence, the other a manner of speech, yet they are complementary and correlative phenomena.[438]

In engaging with the world day-to-day the body literally disappears because we routinely take the body for granted, rather than think about it we merely get on with life. In illness paradoxically the body is vociferous in engaging with itself in pain. The body reasserts itself, makes its presence felt.[439] And yet that very same body becomes dislocated from the world through its dysfunction - through not being in a position to act or engage in that world as it formerly could. Thus the body once more becomes invisible. The key for the patient is to be encouraged to hold on to the person they are, to not lose sight of embodied presence and to embrace illness, to make sense of it.

It has been shown that Principlism acts as a meta-ethic, detached from the needs of complex and dynamic decision-making. Granted the framework may well cover a set of generalised principles which would hold up well within a system of litigation and even within the ethical underpinning of research proposal submission. But the question remains whether such a set of guidelines meets the needs beyond for instance the modern Hippocratic Oath in its

[437] Leder, D., (1990) p91
[438] Leder, D., (1990) p91
[439] Whilst this study focuses on illness, pain and suffering, I do acknowledge that the body comes into view in pleasure, intimacy, exercise and other embodied and bodily experiences.

manifold forms, which many doctors choose to take in order to practise medicine.[440] It may be that the Hippocratic Oath will be considered mandatory in the future, as responsibility for patient care is devolved to the individual patient and accountability for treatment is rendered unclear when monitoring health through medical technology installed in the home becomes routine.[441]

I believe that the notion of care despite its shortcomings, along with a focus on multi-vocality and narrative as integral to care offers greater flexibility, inclusivity, and a more rounded and effective ethical approach. Such an alternative to Principlism that bases morality on the individual when life-changing decisions concerning the welfare of the patient's body are in the balance is critical. The discussions in Chapters 6, 7 and 8 will now turn to the articulation of the proposed approach.

[440] www.pbs.org/wgbh/nova/body/hippocratic-oath-today.html
[441] See Ch.8 of this study.

Chapter 6

The Body Vocal - Narrative

Introduction

'Narrative medicine' borrows its terminology from literature and fiction. As Eakin remarks 'Fiction's critical and irreplaceable consequences are to force readers to recognize the storied shape of reality, to understand in the most basic way that we create meaning by weaving the fragments of life into a plot….'[442] The stories we tell merge with those we hear – in fiction, fairy tales, family legends and sacred texts. Story is the generic term encompassing all manner of genres within its remit, as foundations for cultivating the self.

Narrative by contrast according to Charon captures the 'singular, irreplicable, or incommensurable, …the pleasure of the new, the never seen.'[443] In other words the unique elements that collectively make up the story – a perspective that has especial significance for patient genres in the context of medical encounters. As she maintains, without narrative, the patient cannot grasp what the event of illness means to her and in her terms. And

[442] Eakin, P J., (1999) *How Our Lives Become Stories*, Cornell University Press, Ithaca.
[443] Charon, R., (2006) p13

'without telling or writing about the care of a patient in a complex narrative, the caregiver might not *see* the patient's illness in its full, textured, emotionally powerful, consequential narrative form.'[444] It may be that such narrative vision is 'required in order to offer compassionate and effective care to the sick.'[445]

For Frank a narrative type is the most general storyline that can be recognised underlying the plot and tensions of particular stories.[446] He identifies three types of illness narrative: restitution – restoration of health; chaos – imagining that life will never get better, and quest – seeing illness as transitory. Frank believes that identification of types of story underlies the course for the most appropriate methods of treatment.[447] For instance he describes the telling of restitution illness stories as a way out of 'narrative wreckage.' Using the metaphor of shipwreck Frank sees illness as 'a sense of being shipwrecked by the storm of disease. Storytelling thus becomes the repair work on the wreck.'[448]

Care therefore requires paying close attention to the needs of the other and their story. The story becomes an alternative ethical form. Adam Zachary Newton in *Narrative Ethics* suggests that 'a narrative *is* ethics in the sense of the mediating and authorial role each takes up towards another's story…. Storytelling lays claims upon all its participants, those circumscribed within the narrative as well as those…witnesses and ethical co-creators from without – its readers.'[449]

The rationale for choosing narrative as an appropriate alternative to the traditional bioethical framework of Principlism is the focus of the discussion in this chapter. Prompted by the reality that organ donation and transplantation is distinguished by the involvement of a third person in surgical procedures and outcomes, a positive healing prognosis rests on continued care throughout the process of pre- and post-surgery. The narrative input of both the donor *and* the recipient - beyond the medical history - is fundamental to garner support in times when either physically or emotionally their anxieties may be relieved appropriately by the medical professionals involved. Their experiences are unique in the intervention they are about to undergo, as I discussed in Chapter 3. For the recipient the average waiting time in 2016-2017 for a kidney for example is about two years in which time their condition may

[444] Charon, R., (2006) p13
[445] Charon, R., (2006) p13
[446] Frank, A., (2013) p75
[447] Frank, A., (2013) Chs.4, 5 & 6
[448] Frank, A., (2013) p54
[449] Newton, A Z., (1999) *Narrative Ethics*, Harvard University Press, Cambridge, USA, p48.

worsen to a point where transplantation is no longer an option and the prognosis is dire.[450] Under this circumstance, it may have been possible, given an understanding of the *experience* of the illness to the patient through narrative, for certain life-goals to be fulfilled supported by appropriate medical assistance before they die. Gawande argues that offering a better quality of life in its end stages engenders a sense of trust in an otherwise hopeless situation.[451] Story puts both the patient (as both donor and recipient) and the doctor mutually at the forefront of inclusive decision-making about treatment options even when the patient may be closer to dying.

Story uncovers the everyday personal struggles of people who are trying to make moral sense of their own suffering. The body also acts non-vocally through gesture: smiles, nods of the head, bodily tics and touch for example, all of which provide significant clues to the story the patient has to tell. Beyond symptoms, gestures add a further dimension to diagnosis in myriad ways providing subtle clues to both the mental, spiritual and physical state of the patient. Illness is an unfolding and enfolding process and it is critical for the doctor to assess the patient from diverse viewpoints rather as a 3D hologram, as Bohm suggested, in order to gather sufficient vital data to maximise healing.[452] The practical implications for the medical profession of listening and interpreting patient narrative however are not insubstantial. Although patient input in the form of their developing story might prove to be significant in overall healing processes, and thus offer a better prognosis and fewer visits to the doctor, constraints on doctors' time will doubtlessly prove prohibitive. However, as Charon suggests a suitable method of gathering a diverse variety of data is key to informed decision-making.[453]

The discussion in this chapter centres on story beyond the patient's medical history, and though medical history is vital in assessing treatment protocols, I consider that the patient's own story has significant relevance for their future wellbeing and healing. Clarification of the difference between pain and suffering and the subject of the fear of dying is an important starting point since these issues form the foundation for many a story within a medical context. The conflation of pain and suffering is all too frequent in everyday language use, but they are profoundly different. Pain, however agonising, is structural, suffering is deeply embedded in the subtle energy system, which over time manifests as pain. Suffering as a

[450] See www.nhsbt.nhs.uk organ donation and transplantation for latest figures.
[451] See the section on **Dealing with death** in this chapter.
[452] See Ch.2 p55 of this study.
[453] Charon, R., (2006) Ch.9

result is problematic for medical professionals to treat allopathically. Narrative offers a gateway into patient suffering and thereby a prompt to begin the process of healing often before any treatment takes place.

The distinction between pain and suffering

Pain

Such is the nature of healthcare being dispensed in a routinised manner that medical professionals regularly conflate both pain and suffering. The reality is that doctors treat pain because it is visible, frequently signalled by the patient, able to be monitored and hence treatable, while the subtle problems of suffering which accompany trauma in many cases are underestimated and frequently ignored.

Pain is organic and can be treated at the physical level no matter how intense the pain appears to be. It is a bodily sensation. Medicine has not conquered pain however, though it has developed the means to control pain during much of critical illness. Prolonged pain is the body's response to illness at the gross (physical) level of the body. It is the first thing many people associate with illness and what they fear most. Pain frequently eludes precise definition. We have plenty of words to describe it however: sharp, throbbing, piercing, burning, even dull. But these words go little way towards describing the experience of pain. Pain is a vague concept. Unable to express pain, we come to believe that there is nothing to say. Silenced, we become isolated in pain and that isolation increases it. When we feel ourselves being overtaken by something we do not understand or cannot control, the human response is to create a mythology of what threatens us. Frank suggests that we turn pain into 'it' some kind of enemy to be fought.[454] We hear talk of people 'fighting cancer' for instance. We think pain is victimising us, either because we have done something to deserve it or for some other malevolent reason. We curse it and often pray for relief from it. But pain is not alien - it is from the self. Pain is the body signalling that something is wrong. It is the body talking to itself. Dealing with pain is not war with something outside the body, it is the body coming back to itself. In pain the natural rhythm of life is lost and that loss leads to further losses of plans and expectations of a life that makes sense as a fitting together of past and future. Order breaks down and incoherence takes its place. Pain is thus one of the first experiences an ill person has of being cast out. To regain a sense of coherence, in which

[454] Frank, A W., (2002) pp29-31

pain may have to remain a part, the ill person has to find the means to recover the self she has become separated from.

Under the impact of mind/body dualism in Western medicine, medical professionals have been particularly oriented toward physical bodies and their pain. Thus organic issues are the prime focus of the physician. The patient's illness is consequently transformed into a disease - a recognisable entry into the medical classification system as argued in Chapter 4.[455] Nelson believes that the doctor's concerns therefore become the symptoms, the disease aetiology and history, the pathophysiology and the possible treatment intervention.[456] Historically, we have come to think of physicians as 'high priests' of the body and clergy as 'high priests' of the soul. And whilst this sounds like a very neat division of labour it persists in splitting the human being into two realities and results in distorting the very nature of the healing process.

Suffering

Many ill people when they are patients harbour an intuition that their physicians know aspects of their suffering as no one else can. Amongst the words of others that shape an ill person, the physician's words have particular significance, especially if those words are spoken *to* the person who happens to be a patient, not *about* the patient who contains the disease. Anatole Broyard an American literary critic in relationship with his physician had '…[A] wistful desire for our relationship to be beautiful in some way that I can't quite identify….Just as he orders blood tests and bone scans of my body, I'd like my doctor to scan *me,* to grope for my spirit as well as my prostate….I would also like to think of him as going through my character, as he goes through my flesh, for each man is ill in his own way.'[457] And whilst Broyard did not want his doctor to stop being the technical expert, he did want his illness to be understood as *his* rather than some identifiable disease state.[458] As Frank rather curtly suggests, for many patients' experience of illness is completely different, most end up better advised to find a physician they can use for the medical problem and go elsewhere to talk about healing.[459]

[455] See pp109-110 in this study.
[456] Nelson, J B., (1992 pp125-6
[457] Frank, A W., (2004) pp78-79
[458] Broyard, A ., (1992) *Intoxicated by My Illness and Other Writings on Life and Death*, Clarkson Potter, New York, p44, - Broyard died of prostate cancer.
[459] Frank, A W., (2004) pp78-79

In the distortion of relationships that medical practice perpetuates, both patients and physicians suffer. Lori Alvord understands this suffering as the result of medicine forgetting that 'everything in life is connected.'[460] She like Chinese meridian philosophy, emphasises balance in her surgical work with an awareness of the 'harmony of the entire being' of the patient and the extension of this harmony to the relationships in the operating theatre. She says:

> …[I]llness can be caused by an imbalance or lack of harmony in any area of a patient's life. I began to realise that everything a patient encounters has an impact on her. If illness could be caused by a lack of harmony, could not the same be true for wellness and the ability to heal? It made sense that if the healing environment was more 'harmonious' a patient might return to wellness faster.[461]

Doubtless a great many physicians do see the living subject beyond the text of medical language. But the pressure is strong in the direction of abstraction. While this admittedly serves some practical purposes, such language and style can abstract both the physician and the patient as persons. The case history as a consequence moves in the direction of anonymity and authority and the patient becomes less a person with a story, and more a person *interpreting* her *own* body and her illness. She becomes more the possessor of a body-object with an organically classifiable disease and prognosis. As Nelson suggests, medical practitioners believe in the objectivity of the case history resulting in adherence to the objectivity of medicine itself.[462] Consequently it becomes difficult to deal with the patient as a suffering human being, for suffering is simply not organic. It is that very personal distress we experience when there is a threat to our intactness as persons. Suffering is our interpretation of what is happening. If suffering is seen by the physician as merely subjective, not real and hence not within medicine's domain or is identified exclusively as bodily pain, that which *is real* to the patient becomes trivialised, diminished and depersonalised with the result that suffering is compounded.

It is impossible to treat sickness as something that happens solely to my body without damage to *me*. It is commonly believed that the greater the pain, the more suffering is caused. But that is not necessarily the case. It all depends on the meanings associated with the pain, the interpretations given those physical sensations. According to Nelson, patients can often tolerate writhing pain when they know its source and know it is correctable and temporary. On the other hand patients report considerable suffering from less pain when its

[460] Alvord, L A., & Van Pelt, E C., (1999) *The Scalpel and the Silver Bear: The First Navajo Woman Surgeon combines Western Medicine and Traditional Healing,* Bantum, New York, p12.
[461] Alvord, L A., & Van Pelt, E C., (1999) p12
[462] Nelson, J B., (1992) pp132-134

source and meaning is mysterious to them.[463] That is when pain is not validated by other significant persons. It is at this point that the patient's body in its most intense presence becomes disembodied and alien.

The interpretation of the patient's disease may be at least as important as medical interventions in dealing with suffering and the quality of life. For medical professionals there are two ways of understanding the same reality. One focuses on localising and isolating the offending pain, the other attempts to grasp patients in their totality and understand the meanings of their sufferings and illnesses to *them.* These positions are not antithetical both are needed. Audrey Lorde after having had a mastectomy writes:

> At times, I miss my right breast, the actuality of it, its presence with a great and poignant sense of loss…I have come to realise that that well of feeling was within me. I alone own my feelings. I can never lose that feeling because I own it, because it comes out of myself…I would never have chosen this path, but I am very glad to be who I am, here.[464]

To be fully present with persons as they move from suffering into fully experiencing what that suffering means as they go with it, as they experience reintegration, should be central to the medical enterprise of caring. If suffering is pain that isolates itself in consciousness, absorbing the rest of consciousness, then the true difference is not between suffering and pain. The difference is between suffering which has its cry attended to, and suffering that is left in its own uselessness.

The telling of personal stories can be a form of resistance to suffering. In story the flow of experience is reflected upon and redirected. Stories of suffering have two aspects: one expresses the threat of disintegration that becomes the teller's encompassing reality; the other requires that the old intactness be stripped away to prepare for something new. As Frank points out in *The Wounded Storyteller*, to suffer a person must not only perceive a threat but must resist that threat. The perception of threat is already a weak form of resistance, since the lived flow of experience is disrupted.[465] People in the era of postmodern medicine[466] live simultaneously with both the threat of disintegration and the

[463] Nelson, J B., (1992) p133
[464] Lorde, A., (1980) *The Cancer Journals*, Spinsters Ink. Argyle, New York, p77.
[465] Frank, A W., (2013) pp170-171
[466] Postmodern medicine concerns scepticism of medicine's reduction of patient suffering to a unified/universal and thus static view of the meaning of health and care. In the context of this study postmodern medicine refers to an analysis of the everyday personal struggles of patients, those who care for them and those who observe them who collectively are in a position to affirm what is valuable, meaningful and morally acceptable rather than an acceptance of the status quo which I maintain has been found to be wanting.

promise of reintegration, thus the body stands at the threshold of being unmade but unmaking can be turned into a generative process, that is it stands to be remade.[467] For example chemotherapy easily reduces body strength to weakness, the body is literally unmade as people try to hold onto the promise that the treatment will cure them while at the same time their body is deteriorating, their intactness and integrity as a body-self is disintegrating. Yet people in chemotherapy also believe they are being cared for. Or they believe they ought to believe this, or they have given up believing but still confront others who insist that their treatment is care. The self thus is unmade in contrast to the mind's message of care and the body's message of pain. More importantly such confusion unravels trust. Living with this paradoxical situation is what Frank terms as embodied paranoia. Embodied paranoia is not knowing what to fear most and then feeling guilty about this very uncertainty. Disease and treatment happen to a body/self that is already substantially unmade by a combination of embodied paranoia and scepticism. Suffering places the embodied self in a perpetual condition of 'multiple threatened intactness.'[468]

Suffering becomes useless precisely because any person's suffering is irreducible, being nothing more than what it is, suffering can have no meaning that is beyond the person who is experiencing it. Irreducible sufferings can never be compared therefore, but here the argument has an opportunity to turn on itself. Beyond comparison the existential universal of suffering requires that different forms be spoken of and thus each suffering is part of a larger whole; each suffering person is called to the whole as a witness to other sufferings. Levinas insists that we listen to a further call: the opening to the inter-human.[469] The other who suffers now speaks but cannot hear their own speech, because to be able to hear yourself is already to have found some meaning in helpless suffering. But this speech that cannot hear itself remains a call for help. The voiceless are given voice. And thus from a position of resistance that the disease forces upon the body a voice is found in order to make suffering useful, the storyteller gains a power, a power to tell and even to heal. Listening and telling are phases of healing and so the healer and the storyteller become one. The healing may not cure the body, but it does remedy the loss of body-self wholeness.

[467] Frank, A W., (2013) p173
[468] Frank, A W., (2013) p174-175
[469] Levinas, E., (1988) Useless Suffering, in *The Provocation of Levinas: Rethinking the Other,* Cohen, R A., (trans), Bernasconi, R., & Wood, D., (eds.), Routledge, London, p158.

Dealing with death

Rainer Rilke wrote poignantly about 'death familiar and ours' in the ninth of his Duino Elegies:[470]

> …because being here is much, and because all
> that's here seems to need us, the ephemeral, that
> strangely concerns us. We: the most ephemeral. Once,
> for each thing, only once. Once, and no more. And we too,
> once. Never again. But this
> once, to have been, though only once,
> to have been an earthly thing – seems irrevocable.
> And so we keep pushing on, and trying to achieve it,
> trying to contain it in our simple hands,
> in the overflowing gaze and the speechless heart.
> Trying to become it. Whom to give it to? We would
> hold on to it for ever....Ah, what, alas, do we
> take into that other dimension? Not the gazing which we
> slowly learned here, and nothing that happened. Nothing.
> Suffering then. Above all, then, the difficulty,
> the long experience of love, then – what is
> wholly unsayable. But later,
> among the stars, what use is it: it is better unsayable…
> Namelessly, I have been truly yours, from the first.
> You were always right, and your most sacred inspiration
> is that familiar Death…. [471]

According to Danah Zohar and Ian Marshall, perhaps the most difficult aspect of modern culture is our fear and hence inability to deal with death.[472] Michael Kearney, a doctor in Ireland reported that most of the physical pain we feel in the course of dying really arises from our fear in the face of a process we don't understand, and those who overcome that fear experience less pain and need fewer drugs in support.[473] For some believers in the concept of re-birth, death is a constant companion of life, a constant, further state of present existence. Death is not an ending, but rather a state of on-going existence - a further level of my being.[474] Death, in terms that a quantum theorist would propose infers that my present living form is a state of excited energy, where death is that deeper state of

[470] Together the Duino Elegies are described as a metamorphosis of Rilke's ontological torment and an impassioned monologue about coming to terms with human existence discussing themes of limitations and insufficiency of the human condition and fractured human consciousness, man's loneliness, the perfection of the angels, life and death, love and lovers, and the task of the poet. Dash, B., In the Matrix of the Divine Approaches to Godhead in Rilke's Duino Elegies in *Language in India*: **11:11:11:355-371**

[471] Kline, A S., (2015) (trans), *The Poetry of Rainer Maria Rilke*, Poetry in Translation, Luxembourg, excerpt from the Ninth Duino Elegy.

[472] Zohar, D., & Marshall, I., (2000) pp293-296

[473] Kearney, M., (1996) *Mortally Wounded: Stories of Soul Pain, Death and Healing*, Marino Books, Dublin.

[474] See O'Flaherty, W D., (1980) *Karma and Re-Birth in Classical Indian Traditions*, Motilal Banarsidas, Delhi.

still energy that I carry within me and into which I will one day be reabsorbed.[475] Physicists tell us that all energy is conserved and therefore the amount of energy in the universe never changes, thus the energy that I now am, that which is concretised in my present living body, will exist forever. And so the processes of living and dying simply mean that this borrowed energy that I am will one day take on some other form. My deep being, that deeper sea of potentiality on which my present life is but an ever-evolving wave, has no beginning and no ending.

We are part of a long history of constant creation and destruction of matter and consciousness arising out of the quantum vacuum, traversing space and time for a brief while, and then returning to the vacuum.[476] We are the brief forms that infinite potentiality takes before it borrows us back to create other forms. Life and death are all part of a cyclic process of continuous flows of energy so long as universes are born and die. The seasonal and yearly cycles of nature replay the same drama, as indeed do the individual molecules in our bodies as they come and go through the more persistent pattern of energy that is us. According to Laszlo death is simply a necessary and natural part of the constant transformation of the energy that is life that we see in the changing seasons and in the whole of nature itself.[477] A view that is significant for medical treatment of the body generally and for organ donation and transplantation particularly since Western medical approaches concentrate much effort in preventing death at all costs,[478] sometimes to the detriment of the patient as Gawande rightly points out.

Gawande argues that scientific advances have turned the process of dying into medical experiences, matters to be managed by healthcare professionals. [479] The pattern of bodily decline has changed for many chronic illnesses. Instead of just delaying the moment of decline, treatments can stretch the descent out. Drugs, fluids, surgery, intensive care units and so on get people through. People enter the hospital looking terrible, and some of what can be done makes them look worse. But just when it looks like they have breathed their last, they rally. The trajectory that medical progress has made possible for many people results in increasingly large numbers getting to live out a full life span and die of old age. But

[475] Zohar, D., and Marshall, I., (2000) p293
[476] See Chapter 2 in this study for the discussion of quantum concepts.
[477] Laszlo, E., (2004) Ch.7
[478] It is the rationale behind transplantation medicine and the apparent desperate need for organs.
[479] Gawande, A., (2014) *Being Mortal: Illness, Medicine and What Matters in the End*, Profile Books Ltd., London, pp6-8.

in truth no single disease leads to the end, the culprit is just the accumulated crumbling of the bodily systems while medicine carries out its 'maintenance measures and patch jobs.'[480]

Nevertheless the progress of medicine and public health has been a great blessing, people get to live longer, healthier and more productive lives than ever before. The advances of modern medicine have given two revolutions: a biological transformation of the course of our lives and a cultural transformation of how we think about that course. However the institutionalisation of medicine has given rise to a depersonalised understanding of living and dying. Medical professionals concentrate on repair of health not sustenance of the soul. The battle of being mortal is the battle to maintain the integrity of life - to avoid becoming so diminished or dissipated or subjugated that who you are becomes disconnected from who you were or who you want to be. In general medicine the goal is to extend life. Doctors sometimes sacrifice the quality of existence by performing surgery, providing chemotherapy or even intensive care treatment, for the chance of gaining time later. But people with serious illness have priorities besides simply prolonging their lives.[481]

When there is no way of knowing how long lives will extend, and when we imagine ourselves to have much more time than we do, the impulse is to fight. The simple view is that medicine exists to fight death and disease. Death is the enemy. But the enemy has superior forces. Eventually it wins. No one really has control over the ending of life. Physics, biology and unforeseeable events ultimately have their way, but the point is that we are not helpless either. Courage is the strength to recognise both realities. Death as Beverley Clack points out is important since it leads to discussions of where meaning might be found. Western cultures however ignore death in a variety of ways and in doing so effectively succeed in 'promoting the trivial over the profound.'[482] Death is objectified and placed in a category that makes it more manageable. It is viewed as an accident. If we adopt certain lifestyles, changes in diet, exercise regimes and so on, it can be avoided. Such ideas are predicated upon the belief that it need not occur at all. There is room to act, to shape stories, though admittedly as time goes on it is within narrower and narrower confines. 'The most crucial failure in how doctors treat the sick and the aged is the failure to recognise that they have

[480] Gawande, A., (2014) p26
[481] Gawande, A., (2014) p77
[482] Clack, B., (2002) *Sex and Death: A Reappraisal of Human Mortality*, Blackwell Publishing, Malden, Massachusetts, pp129-130.

priorities beyond merely being safe and living longer; that the chance to shape individuals' story is essential to sustaining meaning in life.'[483]

Susan Block, a palliative care specialist, believes that a large part of the task is helping people negotiate overwhelming anxiety - anxiety about death and anxiety about suffering.[484] Arriving at an acceptance of mortality and 'a clear understanding of the limits and possibilities of medicine is a process, not an epiphany.'[485] There is no single way to take people with terminal illness through the process, but there are some rules according to Block. You sit down. You make time. You're not discussing whether they want treatment X versus treatment Y. You're trying to learn what's most important to them - a process that requires as much listening as talking.[486]

Directly or tacitly, most illness stories borrow their authority from death, and they do so honestly. Walter Benjamin believes that there is no story for which the question 'how does it continue?' would not be legitimate.[487] Thus a story of dying is situated beyond the death of the author. That story continues in other stories forming 'the web which all stories together form in the end.'[488] Each story weaves threads that are original in that person's experience. Yet everything that is said carries the resonance of previous stories, because every expression of despair and act of courage has been told before. A radical hope when death is more or less a proximate prospect is to become part of that web of stories, because the web is paradoxically the possibility of other people's hope.

The importance of narrative in thinking through the body

According to Schneider, enchanted stories, stories of power, scriptural stories, and medical stories do not simply 'transport truth or existential reality - they also create and uncreate it.'[489] She argues that stories, words and images change with experience but the 'way to learn stories is to listen.'[490] The threads of connection between words, images, stories, experience and meaning are tangled and dense. This means that whatever human beings

[483] Gawande, A., (2014) p243
[484] Gawande, A., (2014) p181
[485] Gawande, A., (2014) p183
[486] Gawande, A., (2014) p183
[487] Benjamin, W., (2016), *The Storyteller: Tales out of Loneliness*, Dolbear, S., Leslie, E., Truskolaski, S (trans and eds.), Verso, London, p155.
[488] Benjamin, W., (2016) p155
[489] Schneider, L., (2008) *Beyond Monotheism: A Theology of Multiplicity*, Routledge, Abingdon, Oxford, p107.
[490] Schneider, L., (2008) p108

strive to call truth is inaccessible to human life except 'fleshed in folds of language, culture and interpretation.'[491] The co-constitution of truth with time, place and culture does not discredit the truth as such, instead it makes the vitality of stories less easy to dismiss when pursuing that truth. We might question indeed whether science tells stories in the guise of hypotheses in order to test and undo them so as to make coherent their findings and to guide their investigations. We need the storyteller's genius for getting over the barriers of social or political doctrine to examine what images and beliefs are actually founded upon. For example the storyteller can sometimes more directly, effectively expose the lies and fabrications on which dominant institutions, cultures, classes, races and genders rely for their power. We are painfully aware of the many ways that certainty in the hands of the righteous powerful has historically meant hard times for the outsider or even the oppressed.

Through stories that indicate change, relationality and interconnection, the matter of our existence may be re-ordered - in our daily lives, in our values and priorities in community. Being dynamic through multiple experiences in life, stories themselves are becomings. Since life is fluid, stories that relate to ebb, flow, space and time are creative, purposeful and goal-oriented. They have the potential to build and deconstruct the world. Time collapses and reconfigures in the context of the stories we tell. Time is spatial in stories because 'stories form geometries and meaning in space, in the orientation toward that which takes place in the story, in the story's telling and in the story of the story's telling.'[492] Stories must be told appropriately, however. Honest, authentic stories have such power that once told they are never under the complete control of the storyteller. This is because in part storytellers also become the story. Having the capacity to change the world, stories express the dynamic flow of creation in all its forms. Thus the universal significance of stories is not some truth for all times and places, the significance lies in their potential to prompt questions and offer examples that inform lives lived far from the story's particular time and place. What is real? Who are we? What does this illness mean to me? Arguably these questions are evident just under the surface of contemporary debates about health, reproduction, euthanasia and issues concerning family life.[493]

[491] Schneider, L., (2008) p109
[492] Schneider, L., (2008) p116
[493] Schneider, L., (2008) p131

Narrative as a healing process

Roy Schafer suggests that 'self-stories' are a way out of the narrative describing the wreckage that illness brings.[494] The self-story is not told for the sake of description but rather the self is in the process of a different kind of becoming, of being formed in what is told. In telling these self-stories to others we might, for most purposes, be said to be performing straightforward narrative actions. In saying that we also tell them to ourselves, however, we are enclosing one story within another. This is the story that there is a self to tell something to, 'a someone else serving as an audience who is oneself or one's self….On this view the self is a telling.'[495] The act of telling is a reaffirmation. Relationships with others are reaffirmed, and the self too is reaffirmed. Serious illness requires both. The ill person needs to reaffirm that her story is worth listening to by others. But more importantly she must also reaffirm that she is still there, as an audience for herself, 'in order to keep me available for myself' as Lorde states.[496] Illness is a crisis of self in the specific sense of uncertainty that *I* am still available to myself - *I am still there*. The repair begins by taking stock of what survives the wreckage. The old map may now be less than useful but it has not been relegated. Disease happens in a life that already has a story, and this story goes on, changed by illness but also affecting how the illness story is formed.

Reflections following a kidney transplant

Peter and I lie in the ward,
In neighbouring beds,
Joint beneficiaries.
Released from the tyranny
Of constant changes four times a day,
Mobile once more.

So must the wind feel free to blow
Where it pleases.
No need to plan thirty-two items
To be taken when going away,
No need to plan the times to change
Pleasure indeed.

Peter and I lie in the ward,
Successful transplantees.
Joint beneficiaries
Of some poor wretch who met his death,

[494] Schafer, R., (1981) Narration in the Psychoanalytic Dialogue, in Mitchell, W J T., (ed.) *On Narrative*, University of Chicago Press, Chicago, p31.
[495] Schafer, R., (1981) p31
[496] Lorde, A., (1980) p65

A donor, anonymous to us,
His sole memorial spare parts.

Peter has the left, I the right,
Living kidneys.
I live again, but feel the pain
That pleasure comes from someone's death.
Though one may say for conscience sake
Turn back the clock? It can't be done.
I feel the pain.

Unknown donor, I cry for you,
And yours who mourn with me.
I know I must a burden bear,
A question which I cannot solve.
Am I deserving of your gift?
I feel the load.

R. J Wild after receiving a kidney in November 1988

The stories that ill people tell come out of their bodies. The body sets in motion the need for new stories when illness disrupts the old stories. Thus the body whether diseased or recovered is simultaneously cause, topic, and instrument of whatever new stories are told. These embodied stories have two sides, one personal and one social. The personal side to the narrative of illness is to give voice to the body, so that the changed body can become once again familiar to those stories. As Martin Buber says 'the body does not use speech, yet begets it.'[497] The ill body is certainly not mute - it speaks eloquently in diverse ways in pain and symptoms - but it itself is inarticulate. We must speak for the body, and such speech is quickly frustrated since speech presents itself as being *about* the body rather than *of* it. That the teller's diseased body shapes the illness story should be self-evident. We speak *through* our body, the mind is not separate but diffused throughout it. The obvious social aspect of stories is that they are told to someone, whether that someone is immediately present or not. The less evident aspect is that people do not make up stories by themselves. From many sources, family, friends, popular culture and so on, storytellers have learned the formal structures of narrative, conventional metaphors, imagery and standards of what is and is not appropriate to tell in specific environments or circumstances. Thus, the shape of telling is moulded by circumstances and expectations that 'the story teller has been internalising ever since he [sic] was encouraged to tell the doctor what hurts and then had to figure out what counted as the story the doctor wanted to hear.'[498] Ill people need to tell their stories in order to construct new maps and new perceptions of their relationships to the world.

[497] Buber, M., (1959) *I and Thou,* Smith, R G., (trans), T & T Clark, Edinburgh, p6.
[498] Frank, A W., (2013) p2

The modern experience of illness started when popular experience was overtaken by technical expertise, including complex organisations of treatment. People no longer go to bed and die, cared for by extended family members and neighbours. They go to paid professionals who reinterpret their pains as symptoms using a specialised language that is unfamiliar and overwhelming. As patients they accumulate entries on medical charts and notes which in most instances they are not allowed to read: the charts and notes thus become the official story of their illness. The story that reigns supreme above all others in modern medicine is the medical narrative. The story told by the physician becomes the one against which all others are ultimately judged true or false, useful or not. The American sociologist Talcott Parsons suggested that a core social expectation of being sick is surrendering oneself to the care of a physician.[499] The ill person not only agrees to follow physician regimens, she also agrees tacitly to tell her story in medical terms. 'How are you?' now requires that personal feeling be contextualised within a second-hand medical report. Thus the physician becomes the spokesperson for the disease, and the ill person's story comes to depend heavily on repetition of what the physician has said. But other stories proliferate. Ill people tell friends and family versions of what the doctor said, or rather they are encouraged to, and these others reply by the telling of other experiences that seem to be similar - both those they have had themselves or alternatively have heard from others. Illness becomes a circulation of stories.

The experience of illness begins when ill people recognise that more is involved in their experiences than the medical story can tell. The loss of a life's plan, of a disconnection and destination are not medical symptoms. Yet the scope of medical training does not include helping patients learn to think differently about their post-illness worlds and construct new and different relationships to those worlds. Illness elicits more than fitting the body into traditional community expectations or surrendering the body to professional medicine. Illness is an experience, a reflection on the body self, and the destination that life's map leads to. Illness like the narrative that gives meaning to it is not static, it develops and thus is a becoming. These days the sick role carries the expectation that ill people get well, cease to be patients and return to their normal obligations. But as Frank argues people feel a need to find their voice.[500] They have an alternative construction of self with wide ranging implications of health, of what it means to be healthy and what treatment should be delivered when they become sick. Medicine today claims the body of its patients as its

[499] Parsons, T., (1978) *Action Theory and the Human Condition*, Free Press, New York, Chapters. 1-3.
[500] Frank, A W., (2013) p10

territory, at least for the duration of their treatment. When admitted to hospital for instance or even visiting a doctor, the admittance forms in many instances ask for 'the patient's name' and so we stop being people and start being patients. Our identity as people and the world we once knew are both relinquished, thus we become their patients and end up sometimes living in their hospital.

Increasing numbers of people with varying degrees of articulation and action have begun to be suspicious of medicine's reduction of suffering to its general unifying view. They question their place in medical narratives. Pressures on clinical practice, including the cost of physician's time and ever-greater use of technology, can often mean less time for patients to speak, and so frequently they speak elsewhere, to the media is an obvious example. New evidence resides not in the content of what patients say about medicine but rather recent stories begin in how often medicine and physicians do not enter their stories.[501] This movement involves a profound assumption of personal responsibility. Where Parson's sick role articulated the requirement that ill person's delegate responsibility for their health to physicians, illness responsibility is reduced to patient compliance. The role of the ill person as patient is responsible consequently merely for getting well.[502] Nowadays there is increasing evidence that the ill person takes responsibility for what illness means in her life. Physicians in their turn are responsible more to professional codes for legal reasons than to individual patients - ethical codes such as those proposed by Beauchamp and Childress for instance.[503] According to universalist principles, the greatest responsibility to all patients is achieved when the professional places adherence to the profession before the particular demands of the individual patient. Such professionalism is responsible less to individual people than to 'truth', understood on a number of levels: the factual truth of medical science, the beneficent truth of institutional management in the hospital and ultimately the political truth of administering people's welfare. All of which require the acceptance of the patient's narrative to be surrendered to the medical enterprise.

Morality and illness stories

Stories of people trying to sort out who they are figure prominently in defining the ethic of our times, affording each a right to speak their own truth, in their own words. This voice is embodied in a specific person but it is equally social, taking its influence from the times in

[501] Frank, A W., (2013) p83
[502] Parsons, T., (1978) Chapters 1-3
[503] Beauchamp, T L., & Childress, J F., (2013)

which we live. Frank believes that telling stories of illness is the attempt instigated by the body's disease to give voice to an experience that medicine cannot describe.[504] Storytellers try to reclaim their own experience of suffering and as they seek to turn that suffering into testimony, the storyteller engages in moral action. Morality is thus usefully sought in the everyday personal struggles of people who are trying to make sense of their own suffering and who are witness to sufferings that go beyond their own. Alan Wolfe asserts any professional discipline that observes and attends the ill must accept responsibility for its observations as acts of witness that commit the clinician as a person. Thus responsibility begins and ends with the body. Both storyteller and witness begin with a body and both should commit to that body.[505]

Being responsive to stories of illness and suffering, and equally thinking with them entails telling certain stories over and over in order to hear different nuances of potential meaning as the story develops and is told. It ultimately requires a highly personal grounding of experience: it involves living with the stories and having them shape perceptions of various experiences over time. One of our most difficult duties as human beings is to listen to the voices of those who suffer for the voices of the ill are easy to ignore because they are often faltering, contradictory and confused. However these voices signify conditions of embodiment that most of us would rather forget as they recall our own vulnerability. Listening is demanding, but it is also a fundamental moral act; in listening to the other we are listening for ourselves as well. The moment of witness in the story crystallises a mutuality of need when each is for the other.

Alasdair MacIntyre clearly recognises the importance of witness in his influential description of storytelling:

> …man is in his actions and practice, as well as in his fictions, essentially a story-telling animal. He …becomes through his history a teller of stories that aspire to truth. But the key question for men is not about their own authorship; I can only answer the question, 'What am I to do?' if I can answer the prior question 'Of what stories do I find myself a part?' We enter human society, that is, with one or more imputed characters – roles into which we have been drafted – and we have to learn what they are in order to be able to understand how others respond to us and how our responses to them are apt to be construed.[506]

[504] Frank A W., (2013) p18
[505] Wolfe, A., (1993) p114
[506] MacIntyre, A., (2007) *After Virtue: A Study in Moral Theory*, 3rd edition, Bloomsbury Publishing, London, p216.

Physicians find themselves faced constantly with decisions about 'What am I to do' and each needs either to tell their own story or reflect on their own story in order to answer MacIntyre's complementary question: 'Of what story or stories do I find myself a part?' Most physicians have a problem that MacIntyre would not immediately recognise. Although physicians do find themselves in a role or roles into which they have been drafted, according to Frank many feel limited by the demands of the ethical standards imposed on them. He maintains that many have to tell stories to get themselves out of at least one of the stories of which they are a part.[507] Getting out of an *old* story requires telling a new one, but often there isn't a new story to tell. There isn't an adequate story that is culturally made. By virtue of one or more personal or professional qualities doctors can feel marginalised either to medicine or to society as a whole. Certain marginalities might include ethnicity, gender and sexual orientation. These marginalities prompt the questioning of received values and in such cases where health professionals receive their values from. A new story, a new possibility of being a physician has to be created.[508] It is necessary because the conditions of medical practice have changed and because physicians need to bring a heightened self-awareness to their work. Whilst listening to the stories of patients is both inclusive and valuable, understanding the body language of the storyteller creates a deeper insight into the suffering that their individual story engenders.

In an unspoken voice

Gesture

Entering the space of another requires listening in another guise, for stories are also told by the gestures that accompany them. The body acts, it is an agent of action, and behaviour is the only channel that we can observe directly. Although we might be able to surmise much about a patient's inner life from some kind of resonance with their feelings and sensations, such inferences cannot take the place of the patient also accessing and verbally communicating their own sensations and feelings to the doctor through the story of their experience. However, the doctor can often infer a patient's inner states from reading her body language, the unspoken language of her actions, inactions or tension patterns. As the

[507] Frank, A W., (2004) p83
[508] Frank, A W., (2004) p83

trauma therapist Peter Levine reveals, each of these patterns is charged with meaning and offers further clues to the patient's mental, emotional and physical state at the time.[509]

Paralinguistic clues - gestures - are key indicators of what might be going on for the patient not just in their illness state but in their life generally, adding weight to their narrative. For example interpretation of the clenched fist in non-verbal communication can be seen either as threatening or as the setting of clear boundaries and quelling fear. The wringing of hands may indicate extreme tension. Facial expressions such as smiling or clenching the teeth and bodily posture are also indicative of physical and affective states. Levine advises that bodily reactions are not metaphors; they are literally postures that inform our emotional experience. Tightness in the neck, shoulders and chest and knots in the gut or throat are central to states of fear. Helplessness is signalled by a literal collapsing of the chest and shoulders. Diverse postural attitudes represent action potentials. If they are given permission to complete their meaningful course of action then as Levine confirms, 'all is well'.[510] If not they live on in the body and compound patient trauma and suffering.

According to Erin Manning, a political philosopher and movement specialist, gesture draws our attention to the challenges within expression, leading us to 'the realm of the unsayability of words as completed thoughts.'[511] A gesture acts as a force that renders touchable language's instability, 'challenging language to become an infra-language of interrelation, where the felt is said even as the said is felt.'[512] Gesture reinforces the fact that communication is not linear, that language cannot be pinned down, and words that reach another cannot be completely taken in. Gesture as such has literally nothing to say. It is only relationally that gesture creates the possibility for exchange. However gesture can be used to communicate something to another - that which I don't feel I can adequately voice. Gestures thereby continuously slip outside the lines of organised linguistic structure, enunciating a vocabulary that can exceed everyday language.

Our relationship with others is dependent upon a mutual exchange of sensory data, both external and internal. We gaze, touch and speak, and through a resonance of our sensations come to know ourselves and each other. The overall sense when this process is

[509] Levine, P., (2010) *In An Unspoken Voice: How the Body Releases Trauma and Restores Goodness*, North Atlantic Books, Berkeley, pp143-145.
[510] Levine, P., (2010) pp183-184
[511] Manning, E., (2006) *Politics of Touch: Sense, Movement, Sovereignty*, University of Minnesota Press, Minneapolis, p7.
[512] Manning, E., (2006) p8

synchronised is one of 'belonging and goodness.'[513] Without access to the feeling sense, through bodily sensations, our lives would be one-dimensional. Both our physical life and feeling life, from our most primal cravings to the loftiest artistic creations depend upon embodiment. When embodied we linger in the present moment. When we are fully present we experience more pleasure, wonder and wisdom. Embodiment is thus about gaining through awareness the capacity to feel the ambient physical sensations of aliveness and unrestrained energy as they flow through our bodies. The author and poet D H Lawrence reflected on such a living, knowing body:

> My belief is in the blood and flesh as being wiser than the intellect.
> The body-unconscious is where life bubbles up in us. It is how we know that we are alive, alive to the depths of our souls and in touch somewhere with the vivid reaches of the cosmos.[514]

Touch

We see, hear, touch, smell and taste the divine, who is embodied between and among us insofar as we are moving more fully into, toward, mutually empowering relationships in which all creatures are accorded profound respect and dignity.[515]

Carter Heyward

Touching someone's arm can often indicate mutual understanding of how breathtaking a beautiful sunset is, or proffer a sympathetic response to someone who has lost a loved-one. The most profound moments are frequently silent but words emerge out of silence. According to Gill Westland, we can observe the way that silences are broken perhaps elegantly, roughly or a bursting forth.[516] Wilhelm Reich is of the view that experience 'not only functions before and beyond word language; more than that, it has its own specific forms of expression which cannot be put into words at all.'[517] And furthermore, 'what is described as the spirituality of great music, then, is an appropriate description of the simple fact that seriousness of feeling is identical with contact with the living beyond the confine of words.'[518] Similarly Maura Sills in writing about relationality, maintains that when silence embodies qualities of stillness, warmth and empathic resonance, 'implicate information is

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[513] Levine, P., (2010) p273
[514] brainyquote.com/quotes/quotes/d/dhlawren188634.html accessed 17/06/2017.
[515] Heyward, C., (1989) p94
[516] Westland, G., (2015) *Verbal and Non-Verbal Communication in Psychotherapy*, W. W. Norton, New York, p114.
[517] Reich, W., (1970), *Character Analysis*, Farrar, Strauss and Giroux, New York, p361
[518] Reich, W., (1970) p361

subliminally conveyed and known silently with clear comprehension.'[519] Within this relationality a patient might truly hold their suffering in balance and open to an experience of their human beingness that is beyond words.

Touch is foundational since it is the first sense to develop. Indeed the skin is a vast communication system connecting us with the rest of the nervous system and the external environment. As the skin delineates what is both inside and outside of the body, it creates not only a physical bridge but also a psychological one. The skin provides literal and metaphorical containment; keeping in what should be kept inside and keeping out what we choose to keep out.[520] The skin learns through experiencing touch to process sensory information, however this awareness doesn't necessarily lead to an understanding of its influence. Thomas Dumm reminds us that rejecting touch is possible and sometimes necessary to survive hurt. Yet if such protection becomes entire, it results in negation of life itself. The unavoidable ambiguity of touch conveys both a vital form of relation and a threat of violence and invasion.[521]

Whilst touch can be challenging for some people, the place of touch should not be underestimated in the care and healing of illness and the promotion of wellbeing. Touch empowers those touching and those being touched. It confirms their presence, their immediacy. It restores, it informs, it reassures and embodies the interrelationship between the caring actions of the doctor and the vulnerability of the patient kindling that necessary level of trust that promotes mutual healing.[522] Thus understanding caring through paying attention to what it means to touch and to be touched deepens an awareness of the embodied character of perception, affect and thinking. De la Bellacasa explains 'to think with touch has a potential to inspire a sense of connectedness that can further problematize abstractions and disengagements of (epistemological) distances, the bifurcations between subjects and objects, knowledge and the world, affects and facts…'[523]

Touch through our sensing skin protects us while opening us toward becoming vulnerable to another. To touch is always an attempt to touch the incorporeality of a body, to touch what is not yet. Touch connects bodies. It has an ethical quality because to touch another implies

[519] Sills, M., (2006) In this body, a fathom long… : working with embodied mind and interbeing in psychotherapy, in *About a body: Working with the embodied mind in psychotherapy,* Corrigall, J., Payne, H., & Wilkinson, H., (eds.), Routledge, London. p211.
[520] Westland, G., (2015) p226
[521] Dumm, T., (2010) *Loneliness as a Way of Life*, Harvard University Press, Cambridge, Massachusetts, p158.
[522] Westland, G., (2015) p226
[523] De la Bellacasa, M P (2017), p97

responsibility on behalf of the one doing the touching. Equally I cannot touch you without being receptive. 'For touch must always indicate its source and its source can never be identified by an individual, touch is a singular-plural.'[524] What is interesting about touch reminds us that the body is the medium through which touch can be negotiated. The body is the receiver of the gesture that informs me that paradoxically my body is not one.[525] 'Sign of itself and being itself of the sign: such is the double formula of the body in all states, in all its possibilities.'[526]

The wound of illness lives within the body, trying to resist the shutting down of meaning and sense. It is this resistance, 'this urge to touch another, wound against wound, that potentially creates a community of resistance....'[527] Within this relation new bodies are created and shared - bodies of thought and bodies of knowledge. For the doctor the sense of that difference has the potential to create a body of knowledge, a growing experience of what it means to receive the gift of touch. Touch therefore is informative. It is through an other's touch that my body becomes *my* body, for my body cannot be otherwise than singular and plural - a multiple becoming. It is through the touch of the doctor for instance that a response is elicited, a response that is not necessarily felt or acknowledged by words but through a return of the knowledge gained through the touching initiated by the doctor.

Thus an embodiment of touch is a touch that can never take place unilaterally. Touch belongs first to another. It comes from another, addressing itself to another. Without touch, the body remains unarticulated, unaffected. With touch I enter into communication with you, 'I do not become you' but the space between you and me is created.[528] What I touch is that untouchability, the unknown and the infinite distance that separates me from you. Touch creates time and space, reminding us through every gesture that time and space articulate this very creation rather than pre-existing it. Touching is an event, it is a directional gesture toward a body that has not yet become, not a body in stasis, but a body moved and moving.

[524] Manning, E., (2006) p9
[525] Manning, E., (2006) p11
[526] Nancy, J-L., (1994) *The Experience of Freedom*, McDonald, B., (trans.), Stanford University Press, Stanford, p21.
[527] Manning, E., (2006) p10
[528] Manning, E., (2006) p11

Conclusions

Hospitals trade in endless pieces of specialised information. At best, this information comes together into a coherent medical narrative of the illness that turns out to be a technical account of the disease, its possible cause and expected progression. Technical accounts however concern the interaction of non-sentient objects thereby lending little meaning to illness and suffering and inhibiting the kind of story telling that can make the experience meaningful. The fundamental problem with stories of recovery and success lies in the considerable weight of institutional authority and expectation that results in crowding out other forms of storytelling. Whilst such stories are not without veracity, they can exemplify the sad but profound truth that communicability of patient experience is frequently lacking. Walter Benjamin writes of medical institutions: 'Almost nothing that happens benefits storytelling; almost everything benefits information.'[529] NHSBT for example advertise for organ recipients and donors to send in their stories for inclusion on their organ donation website. Those stories *receiving approval* will be written up by a journalist in a manner that 'tend[s] to lead directly to people becoming donors or registering to donate.'[530] In other words the stories are sanitised to provide a positive advertising mechanism for overcoming organ shortage. One such story recounts the experience of a kidney donor who was reported as 'gently jogging in three weeks, back in work on light duties after four weeks and *pretty well* recovered after six weeks.' And who declared 'It was a life-affirming experience. If I had a third kidney, I would happily do it again.' It would have been interesting to discover what he meant by life affirming and how his recovery played out long term.[531] Equally 'Real Life Stories' available on the NHS website provides stories of 'People who have benefitted from receiving a transplant.'[532] The reality of living with a 'new' organ in the body substantially alters the circumstances of recipients and donors whose stories would be valuable.

There seems to an institutional climate of fear around sufficiency of solid organ donations, yet figures substantiate that the ratio over ten years or so has barely changed.[533] This would lead to the conclusion that some deeper issue is at stake that requires teasing out through a different mode of narrative and recording method. Underpinning my point, a recent book

[529] Eiland, H., & Jennings, M W., (2002) (eds.), The Storyteller in *Walter Benjamin Selected Writings* vol.3, 1935-38, Harvard University Press, Cambridge Massachusetts, pp147-148.
[530] http//nhsbtdbe.blob.corewindows.net/umbraco-assets-corp/4148/ accessed 28/09/17.
[531] See www.nhsbt.nhs.uk/how-we-help/saving-lives/patient-and-donor-stories/ accessed 28/09/17.
[532] See http//www.organdonation.nhs.uk/real-life-stories/ accessed 28/09/17.
[533] See footnote 11 of this study.

What's in a Story? Lessons from Reflections in General Practice containing more than one hundred stories written by dozens of authors might have been a step in the right direction. A comprehensive set of general practitioner reflections has the potential to provoke thought in a wider medical readership. Sadly not. It turns out to be accounts of errors, missed diagnoses, and contradictions, a learning manual for general practitioners. A missed opportunity; by fitting into a template for 'what I have learnt' rather than breaking out of it, much of the power of storytelling is lost. An encouragement to think more critically about these stories and what they might mean for the narrator, patient and medical practice/ethics might instead have unleashed the potency of medical storytelling.[534]

Whilst case histories and narrative accounts of successful transplants are no doubt helpful for the medical professionals, they do little to represent what illness and a subsequent transplant means for the patient beyond their physical symptoms. Neither do they account for the longer-term experiences of the donor or their relatives, nor the relatives of the organ recipient. There is considerable disruption to all in those circumstances, rendering care and support networks that build trust essential when those involved are feeling at their most vulnerable. It is pertinent that whatever financial and resourcing levels pertain at the time, positive healing outcomes for all concerned are maintained, predominantly for the patient, but equally for the donor and the relatives who have to cope with the aftermath of complex procedures which will affect their everyday lives well into the future.[535] In the long-term this has financial consequences, it saves money, but more importantly insures improvement in health and wellbeing and potentially leads to fewer visits to medical agencies. All too frequently the ill person and those around her are subsequently left to deal with the consequences of what has not been recognised. If the ill person dies, those who survive must deal with all that was not said, the unfinished business of a life closed out in a setting where dying is a problem of management not a continuity of experience. And those ill persons who recover must recover not only from the disease but also from being a patient. According to Frank 'This recovery will proceed far more smoothly if the person within the patient has been recognised throughout the period of illness by those involved in the process of their healing.'[536]

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[534] Orlands, D., Charlton, R., & Finnikin, S., (2017) (eds.) *What's In A Story? Lessons from Reflections in General Practice,* Royal College of General Practitioners, London.
[535] www.nhshistory.net/midstaffs.pdf
[536] Frank A W., (2002) p57

Becoming a storyteller, the narrator has her own ethic - a *telos* for life to aspire to. The crucial test of the story may well be the sort of person it shapes. Stories have the capacity to engender hope in the possible hopelessness of illness. Hope begins with having sufficient confidence that an individual's life will have a future story. Most hope consequently requires a belief in the capacity to affect how the story unfolds. Beyond those minimum conditions, hope means imagining that life can be at least worthwhile and at best valuable. Those who are ill might imagine living a life that is relatively speaking, 'good'. That life is not as the person wanted it to be. Instead, 'good' for those who are ill means life lived in conditions the person did not choose and could not avoid, but has discovered value in life lived in those conditions. Perhaps what is needed is what Frank calls 'intransitive hope' - a hope that has no specified object or objective.[537] It is an openness and a flexibility that allows hope for healing even in the face of a grim clinical prognosis. Healing itself is not a fixed outcome it denotes a range of possible conditions all of them different from a medical cure.

Charon argues that narrative ethics is not an independent method that promises to replace all existing efforts in the field of medical ethics. As long as clinical ethics remains grounded in universally applicable principles and adjudicatory rules to health care conflicts, so long as limited liability remains the guiding principle governing its vision of the practice of medicine, clinical ethics limits itself to 'imagining variations. It continues to play the broken record.'[538] The value of narrative contributions lies in their ability to enhance medical caregivers' recognition of the complexity of treatment decisions. As such, narrative plays a crucial role by leading physicians to recognise the moral dimension in every medical encounter since it helps to ground difficult medical decisions in the concreteness and specificity of each patient's life. Barry Hoffmaster suggests that the moral imperative of narrative ethics is not clinical adjudication but personal becoming, of evolving and growing in spite of the illness. It is an ethics of commitment to shaping oneself as a human being. Individual stories are the medium of this shaping, and the shaping itself is the story of each life.[539]

Patients need words to speak the truth about illness, words in which they try to fit a world that seems worth believing in. Although experiences are very much individual, such experiences are understood in relation however. In this vein, Chapter 7 will take up the significance of multiplicity in complexity, of otherness and of relationality establishing the

[537] Frank A W., (2013) p205
[538] Charon, R., (1994) Narrative Contributions to Medical Ethics: Recognition, Formulation, Interpretation and Validation in the Practice of the Ethicist, in *A Matter of Principles: Ferment in U.S. Bioethics*, DuBose E R., et al., (eds.) Trinity International Press, Valley Forge p 277.
[539] Hoffmaster, B., (1994) The Forms and Limits of Medical Ethics in *Social Science And Medicine* : **39:9:1161**

notion that the body is much more than individual containment, but rather a wave of possibility, power and potential caught up in dialogue with the voices of multiple others.

Chapter 7

The Body as Multiple, Relational and Other

Mutuality involves wrestling more fully to embody friendship. It involves learning to stand and walk together and to recognise and honour the differences we bring to our common ground. It requires risking through fear, not without it to be friends. It means working together on our frustrations, hurt, anger, confusion and conflicts. It is a process of getting unstuck, of coming into our power together. It is the way of liberation, of calling forth the best in one another and, in so doing of empowering one another to be who we are at our best.[540]

Carter Heyward

Introduction

If bioethical stances are to progress with any degree of confidence, a more fluid interpretation of what is 'good' for individuals and for those who are ill in particular is vital. I have proposed that viewing the body differently will contribute effectively towards accomplishing the aim of grounding the seemingly intractable complexities of technical advancement especially within transplantation medicine, in order to render with greater clarity, the effect on patients, donors, family and medical professionals. Establishing a

[540] Heyward, C., (1989) p105

rationale for narrative through the processes of multi-vocality, that is by gaining views from both expert and non-expert, from protagonist and sceptic, I believe will offer greater insight into development of any approach within an ethic of care.

People tell stories not just to work out their own changing identities, but also to guide others who will follow them. In so doing their act of narration does not provide a definitive map for others but rather is an act of witness to their own experience of reconstruction, whether it be of their lives or their story. Story telling is for another just as much as it is for the self. For the storyteller offers themselves as guide to the others' self-formation. Frank believes that 'The moral genius of storytelling is that each, teller and listener, enters the space for the other. Telling stories attempts to change one's own life by affecting the lives of others.'[541] Ill people still surrender their bodies to medicine, but increasingly try to hold onto their own stories. Refusing narrative surrender however becomes an exercise of responsibility. A sense of responsibility to the common-sense world that in turn represents one way of living for the other.

This chapter considers otherness from the early beginnings of what it means to be other through subject formation, awareness of the body self in relation, the concept of multiplicity, the importance of dialogue, and the meaning of otherness in medicine seen through the gaze of care and compassion considered central to the concept of healing.

The formation of self

A body in the world is much more than individual containment. It is a complex assembly of feeling that is active between different settings that constitute the whole. It is individuation before it is self.[542] Connected environments are active and always in concert with the becomings they engender. Becoming self is one of the ways in which the fluid wave of beingness expresses itself, but never toward a totalisation of self - always toward continued individuation. The self not being contained, is a fold, a wave of immanent expressibility and power:

> To think individuation it is necessary to consider being as not a substance, matter or form, but as a tensile oversaturated system beyond the level of unity.[543]

[541] Frank, A W., (2013) p18
[542] Individuation – the act or process of making somebody or something separate and distinct from others.
[543] Simondon, G., (1995) *L'individu et sa genèse physico-biologique*, Jerome Millan, Grenoble, p23.

Gilbert Simondon's premise is simple: individuation whether subject or object according to traditional categories, comes to be.[544] Thus the span of becoming is broader than the concept of a being. All individuation is *more* than an individual. The individual is always moving into its own and beyond. And so every actual occasion carries within itself the more-than of its taking form. 'Force is everywhere active, on time-lines that intersect with the occasion at hand, and on transversal lines that extend beyond it or circle through it.'[545] The body is a phase of being. It is a relative fact. Every phase comprises individuation and the pre-individual. These two cannot be thought singly according to Simondon. Individuation is an unfolding process and the force of the pre-individual reminds us that life is neither *in* the individual nor *outside* it but in what surpasses it while accompanying it. It is the germ of potential in every activity. This means that all resolutions - as body, as individual, as object - are more than the forms they inhabit. A body is always more than one: it is the *how* of the multiplicity of its emergence, not the *what* of its form.

Daniel Stern emphasises that tendencies developed in early infancy do not build toward a contained view of self, but rather lead toward the creation of a multiplicity of layers each of them differently expressive under variable conditions.[546] Therefore a core sense of self involves a non self-reflexive awareness. Preverbal awareness is linked to direct experience where direct experience is of the order of the event. Like William James' concept of 'pure experience', defined as the virtual or unconscious edge to all lived experience, direct experience can be likened to an immanent wave formation through which events become experience.[547] Direct experience takes place not in the subject or in the object but in the *relation* itself. Unlike the idea that the self rests in a containment of skin, Stern proposes that selves build onto and through one another in intimate relation with a changing environment: '…[several] senses of the self do exist long prior to self awareness and language.'[548] There is no stable identity that emerges once and for all. Becoming human, although a momentary cohesion, is nonetheless a sense of self that remains coloured by the interweaving of forces that both direct and destabilise the self's development into an 'I'. The infant is not a passive slate into or onto which the world can be written. The infant is an emergent experience, an individuation of interweaving layers active in the creation of

[544] Simondon, G., (1995) p23
[545] Manning, E., (2013) p16
[546] Stern, D., (1985) *The Interpersonal World of the Infant: a View from Psychoanalysis and Developmental Psychology*, Harper Collins, New York, p6.
[547] James, W., (1912) Does Consciousness Exist in *Essays* in *Radical Empiricism*, Longmans Green and Company, London.
[548] Stern, D., (1985) p8

physical, psychological and social development, as Gilles Deleuze states:

> The life of the individual has given way to an impersonal and yet singular life which foregrounds a pure event that has been liberated from the accidents of internal and external life, that is from the subjectivity and objectivity of what comes to pass.[549]

When we speak about subject formation, Judith Butler argues we invariably presume a threshold of susceptibility or impressionability that may be said to precede formation of a conscious and deliberate 'I'.[550] This being that I am is affected by something outside of itself, understood as prior, activates and informs the subject that I am. I am already affected before I can say 'I' at all.[551] As discussed in Chapter 6, the senses are primary. We feel things, undergo impressions prior to forming any thoughts, including any thoughts we might have about ourselves. So norms, conventions, institutional forms of power are already acting prior to any action I may undertake. Prior to an 'I' that thinks of itself, from time to time, as the seat or source of its own actions. I am not only already in the hands of someone else before I start to work with my own hands, but I am also in the hands of institutions, discourses, environments, including technologies and life processes, handled by an organic and inorganic object field that exceeds the human. 'I' am nowhere and nothing consequently without the nonhuman. 'The unwilled character of this dependency is not itself exploitation but rather open to it.'[552] Furthermore susceptibility alone does not explain passionate attachment or indeed falling in love or a sense of betrayal or abandonment. Yet all of those things can follow depending on what happens in relation to those who move and affect us. We do not always know or cannot always say who touched whom first or what was the moment of being touched and what was the moment of touching. The moment is fluid and dynamic or 'transitive.'[553] It is a becoming through momentary occurrence.

The body as multiple and relational

The 'other' is critical to human nurture and development, for as Butler proposes problems occur if the 'I' is separated from the 'you' or indeed the 'they' - that is from those without whom the 'I' has been unthinkable - for doubtless severe disorientation will follow.[554] Who becomes this 'I' after such a break with those formative relations and what if anything can

[549] Deleuze, G., (2005) *Pure Immanence: Essays on Life*, 2nd edition, Zone Books, New York, p28.
[550] Butler, J., (2015) *Senses of the Subject*, Fordham University Press, New York, p1.
[551] A concept that raises the question of the relevance of autonomy under any conditions, be it bioethical or otherwise.
[552] Butler, J., (2015) p7
[553] Butler, J., (2015) p7
[554] Butler, J., (2015) p9

that 'I' still become? If dependency on those others was once a matter of survival and now continues to function psychically as a condition of survival then certain kinds of breaks will raise the question of whether the 'I' can survive.[555] The 'I' may undergo radically conflicting responses as a consequence of its separation from those formative relations but paradoxically only with such a break does it now stand to survive. Such ambiguous relationality demonstrates that the 'I' is multiple and not easily separated from those relations that made the 'I' possible, but the possibility of that break becomes part of the history of 'I' which 'actually opens up a liveable future.'[556]

The crucial difference between those patients requiring a replacement hip for example and those requiring a transplanted organ, as I have maintained throughout this thesis, is the necessary intervention of a third person, the donor, to alleviate the problems of organ failure in most cases. The 'I' is thus blended with the anatomical part/s of an 'other' be they visceral or mechanical and this raises ethical questions of the value and identity of the person, either as patient or donor - for both, bodily integrity becomes an issue. If the donor is not a 'formative relation' how does the removal of a kidney for example and its transplant into a different body impact on the lives of those affected? Is there any difference to the structure and functioning of the body at some level far beyond merely its anatomy and physiology? Does gender have any significance for transplanting female organs into male bodies? Does the donor grieve in some sense for the organ they have lost? And what about organs grown in pigs or sheep for transplant? Should we be concerned for the animal? Of course we should.[557] But questions remain largely unanswered save for scant anecdotal evidence recording transient changes in the form of drinking habits or changes to dietary choice and personality.[558] In her book *The Transplant Imaginary*, Sharp comments: 'Involved professionals - be they surgeons, transplant nurses or social workers, or organ procurement specialists - invest significant effort in denying the strange uncanny, and troubling aspects of organ transfer, a stance facilitated by elaborate forms of rhetorical policing, word play, and metaphorical representations that both objectify "fleshy" parts and obscure their troubled human origins.'[559] That the body is multiple is undeniable, how it is conceived and treated is another matter.

[555] Mother and baby or doctor and patient for instance.
[556] Butler, J., (2015) p10
[557] See Ch.8 p190 in this study.
[558] Sylvia, C., & Novak, W., (1998) pp89-90
[559] Sharp, L A., (2014) p12

Multiplicity thought through bodies demands a different kind of conceptualisation than the generalities that categorical ideas allow because bodies fail to be general. Multiplicity itself is a language of its own. It is a hybrid, a heterogeneous mix of the body in a constant state of flux. Could this mean that the body can easily assimilate the transplanted body parts of another however? For the body perceived as a wholistic entity where each anatomical system at the particle level is intimately interrelated with every other, transplantation becomes problematic. According to medical professionals, a transplanted organ never truly adapts to its 'new' environment.[560] Multiplicity entails an understanding of change in relationship, it is not a 'disintegration into disconnected manyness.'[561] Always context dependent, rather than absolute, multiplicity is tied to existence in every way - tied to time, space and experience and thus forever changing. Not static it extends outwards and adaptively encompasses a great deal. Multiplicity breaks with long held concepts of unity and oneness, but sits in opposition to the ontological status of stasis prevalent in universal monotheism that 'opposes fluidity, change and partiality.' As Schneider suggests, universal monotheism requires 'strong claims' of infinity, inconceivability and eternity in order to maintain its universality in a world of difference and particularity.[562]

The fluid nature of humanity is beyond the one/many divide, opposed neither to oneness and unity but limited by both. Unity does occur in partial and temporal ways. Without unity there would be no possibility of societies. Functional unity for instance is necessary to survive and create meaning. A human being is a meaningful unity *as well as a continuous stream of change*. And oneness is significant for each person, impossible to exchange because of the uniqueness of elements intertwining and thus contributing to rendering that person a distinct identity. Consequently relating to an other in her own in-exchangeability and distinction through categories such as doctor, patient and co-worker is unrealistic. We might define doctors and so on as 'categories of convenience', because they compress the other distinctions into abstraction and make actual presence meaningless.[563] Categorisation prompts us to ask - what do you do? - rather than relating meaningfully to the person in our presence. On the other hand to be fully present to the bodies of others, to the body of the world, in others words to being fully there, embodied presence breaks open static categories of persons *and* things, or more importantly of persons *as* things.

[560] Which is the reason why multiple drug regimes are in place so that organ/s are not rejected.
[561] Schneider, L C., (2008) p198
[562] Schneider, L C., (2008) p199
[563] Schneider, L C., (2008) p194

The epistemological assumptions raised by the concept of multiplicity have profound consequences for the language/meaning used in transplant medicine. A donor given this awareness is not merely a donor and neither is the process of donating. These are complex multiple interrelationships sharing certain common characteristics but differentiated when the donor having undergone surgery becomes a patient. Whilst the donor as person is far more than medical terminology can either express or the professional might have fully thought about, the transition from a participant in the transplantation process to a patient/person post-operatively thereby chimes more readily with the transition which the patient/recipient/person undergoes when the new organ has been implanted. The loss of information and identity between these diverse positions and ethical interconnections is potentially immense. The question of how transplant procedures have impacted upon the donor and the recipient as persons is surely not only extremely valuable for future healing and wellbeing in terms of how patients manage their lives, but also for those carrying out the procedures in order for improvements in learning, caring provision and subsequent decision-making to be consolidated. In short an approach to care seen through the lens of narrative appears even more compelling.

According to Schneider, multiplicity is the embodiment of love through a certain god-like presence. Love in the name of multiplicity is temporal, present, embodied, transient, creative, and thus ethically instantiated. It is the result of an intentional presence; an encounter that Bonhoeffer describes as authentic and is the very foundation of change when people show up openly and risk it all. It is the possibility of connection and so of becoming and thereby is both coming into intimacy and irretrievably passing away. Bonhoeffer argued for authentic encounter as the 'event' of divine presence.[564] And Buber suggested that authentic encounter is recognition that another is not an 'it', not even a 'you', but a 'Thou', a presence of absolute worth, utterly in-exchangeable for another.[565] This kind of love is the being of divinity and so it cannot be severed from the question of ethics - because when it is separated we too become separated from ourselves, from others and from the world, a world in which we exist and live. Multiplicity always returns to the fluid, ephemeral experience of being present in this world - a being present that is mandated by renewal or incarnation. Witness, accompaniment, protest, comfort, solidarity, the courage to see and the courage to sin - the sum total of more than who we are - these ethical stances can be understood through the gaze of multiplicity. Thus ethics understood from the notion of

[564] Bethge, R., (ed.) & Bowden J., (1966) *Christ the Center*, lectures delivered by Dietrich Bonhoeffer in 1933, Harper and Row, New York.
[565] Buber, M., (1959) p6

being present cannot be summed up in simple rules but it can be characterised by focussing on the presence of and importance of others.[566]

Utilitarian ethical models such as Principlism built on simplicity of societal norms and mores is an economy of identity because sameness becomes the basis for establishing real from unreal. Something therefore is real if it confirms the same as the known. As Schneider maintains otherness or difference especially otherness that cannot be somehow resolved into a recognisable frame of sameness indicates an error in knowledge or in judgement precisely because by this reckoning otherness cannot be real. Thus if to be is to be the same, Schneider argues 'to be other is a dreadful loss of existence.'[567] Irigaray moves past this reasoning to actually think the other as the other, to imagine a rationale that is not bound to this universe. She suggests we do so by 'thinking the body' since despite everything we try to effect to control, repress, deny, or compress them, bodies do tend to flatly resist oneness or simplicity.[568] Phrases such as 'we are all in this together', or 'we are far more united, and have far more in common than the things that divide us'[569] are symptomatic of a reduction of thought, and a simplicity which denies the complexity of humanity as multiple. Within a fluid multiplicity, there is no One (as for instance God or indeed any power) against which the one can be compared or measured. And as Rosi Braidotti points out 'the only constant at the dawn of the third millennium is change' so that the aim of trying to search out a logic of multiplicity is not to locate a universal and final closure for thought that will always and everywhere successfully resist reduction.[570] Multiplicity is not the same as the many. It does not refer to a bunch of separable units - many ones. Multiplicity results when the ones so constitute each another that they come to exist *because of one another*. Multiplicity is complexity writ large. The whole is constituted by the parts, but then the parts themselves are also constituted by their participation in the whole. As Jean-Luc Nancy explains:

> The One as purely one is less than one; it cannot be, be put in place, or counted. One as properly one is always more than one. It is an excess of unity; it is one-with-one, where its Being itself is co-present. [571]

[566] Schneider, L C., (2008) p202
[567] Schneider, L C., (2008) p88
[568] Irigaray, L., (1985) p88
[569] See the maiden speech of the late Labour MP Jo Cox at www.independent.co.uk/news/uk/politics/jo-cox-dead-maiden-first-speech-a7086106.html accessed 16/06/2016.
[570] Braidotti, R., (2002) *Metamorphosis: Towards a Materialist Theory of Becoming*, Polity, Cambridge, p1.
[571] Nancy, J-L., (2000) *Being Singular Plural*, Richardson, R D., and O'Byrne, A E., (trans), Stanford University Press, Stanford, p39.

In other words a 'pure' one is logically/mathematically impossible because as such it implies no other, no relation and therefore can neither be 'seen' nor counted since counting requires the defining presence of others.

Medicine and otherness

Whether being ill or giving care, act without judgement on your body or the body before you: see it and know it only as what is, as much divinity as dust, part of a cosmos you can trust.[572]

Marcus Aurelius

Medicine involves a deep appreciation of 'the other' of otherness. Part of the remit of physicians concerns how to encounter patients who are radically different in the material, intellectual and spiritual conditions of their lives for they differ in the choices that express their values. The doctor and the patient may not share the same values and since these are so embedded in human being, difficulty arises in imagining how each could find their own individual values compelling. In such an instance dialogue potentially breaks down and either disagreement or the diminishing of trust ensues.

What would it mean for physicians to practice identification with the ill? How the physician conceives of the patient would shift surely, and part of that shift would be a corresponding change in how physicians imagine themselves. Mikhail Bakhtin links any understanding of the other with an understanding of the self.[573] For many patients, the standard medical response as they are sat before the physician is not of the person *per se*, but rather a question of *patient* attributes, beginning with vital signs, moving through diagnosis and treatments and finally the possibility of a social history consisting of family status and employment. Recall however that multiplicity entails that *she* exists only in relation to '*I*' and thus who *she* is depends on who *I* am, as *I* address myself to this other. Thus to talk *about* people, not *with* them closes some passageway that ought to remain open. The patient is after all a person with all the attributes personhood entails. Identification with the ill is not a burden added to what physicians already bear: it potentially lightens what they must bear. Since people exist on the boundary with others, 'who am *I*?' is always changing in response to 'who are *you*?' - our identities can never be stable. Identification with anyone means, paradoxically, recognising that they are perpetually not identical to what I believe them to be, for instance in a specific role that defines them as 'ill'. For Bakhtin's trope of the moral

[572] Chase, M., (1998) (trans) *The Meditations of Marcus Aurelius*, Harvard University Press, Cambridge, Massachusetts.
[573] Bakhtin, M M., (1984) p251

life there is 'no final, finalizing discourse that defines anything once and forever.' No last word can be said about this *you*, whose horizons of possibility remain open. 'As long as a person is alive, he lives by the fact that he is not yet finalized, that he has not yet uttered his ultimate word.'[574]

Patients grow through others' embodied dialogues with them, how others touch them, speak with them and stimulate their senses. Their capacity to outgrow emanates from between themselves and others, not only from within. Patients remain unfinalised even in disagreement so long as others sustain dialogical relationships with them.[575] Speaking *with* the other, not *about* her, is one way to recognise the unfinalisability of the other. Speaking *about* shuts down the dialogical interplay reducing communication to monologue. Most physicians are taught monological medicine. According to Bakhtin the doctor is the one cognitive subject in the consulting room and the patient is the object for that cognition. Thus he asserts that physicians discover for themselves that this model doesn't work for them personally. Identification with others requires giving up such a stance. Dialogue on the other hand creates the possibility of becoming a person:

> Everything that pertains to me enters my consciousness, beginning with my name, from the external world through the mouths of others (my mother, and so forth), with their intonation, in their emotional and value-assigning tonality. I realize myself initially through others: from them I receive words, forms, and tonalities for the formation of my initial idea of myself… [576]

Frank observes that the physician often feels the monological authority of being the single unquestioned voice.[577] The patient feels the monological passivity of having this other pronounce their truth. But healing requires an equality of input to the discussion. For the patient, the physician's healing presence lies in her dialogical capacity to take raw and solitary words of pain and suffering and, dropping the tone of professionalism, express those words through a human voice, creating something new between them. For the physician, the patient's healing presence elicits a new response to the question 'Who am I?' that understands 'I' as coming to be for the first time as the subject of the patient's address, which is the patient's face - her vulnerability.[578] For Irigaray that ethical relation will be represented by the question, 'Who are you?' which seeks to cross the difference that divides

[574] Bakhtin, M M., (1984) p59
[575] Bakhtin, M M., (1986) *Speech Genres and Other Late Essays*, McGee, V W., (ed.), University of Texas, Austin, p138.
[576] Bakhtin, M M., (1981) *The Dialogical Imagination*, Emerson, C., Holquist, M., (eds. and trans.) University of Texas, Austin, p xx.
[577] Frank, A W., (2004) p103
[578] Frank, A W., (2004) p103

the doctor from the patient, but not to cross that difference through a substitution that presupposes the equivalence and interchangeability of their positions. In other words 'Who are you?' is the definitive question for the doctor. In crossing that divide, it seeks to know what is different, but to know it in such a way that what is different is not assimilated or reduced to the one who wants to know.[579]

Bakhtin uses suffering as his example to propose a different way to understand how people relate to each other. Like Irigaray, he does not believe in the 'exact passive mirroring or duplication of another's experience within myself.'[580] Recall that Broyard did not expect his doctor to suffer with him for instance.[581] So long as 'suffering with' is understood as mirroring or duplication it isn't possible, but a dialogical suffering *with* is. Instead Bakhtin proposes a different way to comprehend how people understand each other. The other's suffering as co-experienced by me is in principle different from the other's suffering as she experiences it. This distance cannot be bridged. But between them a completely new interrelationship can be developed.[582] There can be a co-experienced suffering that is not the same as that which either person individually experiences - consciousnesses do not merge but exist as a new formation, a new wave I would suggest that is available, as a space of consolation, between self and other. In contrast, agony is being locked within, unheard and unmoving. Going to the space of co-experienced suffering can be consolation. The doctor who creates this alternative space of co-experienced suffering does not pretend to know what the patient is going through. Rather she allows the patient access to the space of what they are going through together, the space that doctor and patient can create in the limitations of illness.

Dialogue in a medical setting

Individual experiences brought to medical meetings and procedures will have significant input into the decision-making process and the prognosis of the patient.[583] Symptomatic of the traditional way that some professionals deal with patients is exemplified by a BBC Breakfast TV article broadcast in September 2017, when a hospital doctor discussed how he dealt with traumatic incidents at work, admitting that he just got on with the job at hand and

[579] Burke, C., & Gill, G C., (trans) (1993): Irigaray, L., *An Ethics of Sexual Difference*, Cornell University Press, Ithaca, p157.
[580] Bakhtin M M., (1981) p102
[581] See Ch.6 p137 in this study
[582] Bakhtin M M., (1981) p103
[583] See Ch.6 p137 in this study.

dealt with the emotional outcomes post-trauma subsequently. Thus finalising of interaction and discourse becomes a real issue. Charon argues that many health professionals are uncomfortable around emotion and uneasy when the medical interview is not crisply and evidently focused on the physical problem at hand.[584] They structure the conversation as it unfolds by interrupting the patient so that she furnishes only medically relevant information. And Howard Waitzkin reasons why interruption and finalising might occur: 'the story may not contribute to the doctor's cognitive process of reaching a diagnosis; the patient's version of the story may be confusing or inconsistent; telling the story may take more time than is perceived to be available; or parts of the story may create feelings that are uncomfortable for the doctor, the patient, or both.'[585] The point is that stories that are uncomfortable are all the more reason for them to be narrated, otherwise the interrupted voice remains silenced and the self as suffering proliferates. Genevieve Lloyd suggests: 'It is a matter rather of seeing everything that happens - whether it be grand or unbearably petty, as integral to the being of a self which, if it were to recur at all, could do so only in its entirety.'[586] Whether the story is uncomfortable or not for illness stories to be worth listening to there is a mutuality of responsibility that is new both to illness experience and to medicine. This entails discovering the truth in the narrative and telling that truth. The physician equally must be the witness and take the complementary responsibility for receiving the story. It requires the patient to tell the physician not what they want to hear but what the patient knows to be true because they have lived it. Since the story is known already within the body, truthful recounting allows the ill person to begin healing by reclaiming their own self.

Illness stories are told by bodies that are themselves living testimony. Others have the story as content, but only the ill person herself can *be* the story that is the fullness of the testimony and what that testimony demands. Illness stories require the interplay of mutual presences: the listener must be present as a potentially suffering body to receive the testimony of the suffering body as embodied teller. The disease that sets the body apart from others becomes, in their story, the common bond of suffering that joins bodies in their shared vulnerability. As Charon remarks: 'wounded people may be cared for but as storytellers they care for others. The ill and all those who suffer can also be healers.'[587]

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[584] Charon, R., (2006) p98
[585] Waitzkin, H., (1991) *The Politics of Medical Encounters: How Patients and Doctors Deal with Social Problems*, Yale University Press, New Haven, p28.
[586] Lloyd, G., (1993) *Being in Time*, Routledge, Abingdon, Oxford, p20.
[587] Charon, R., (2012) The Narrative Road to Empathy, in Spiro, H., et al., (eds.), *Empathy and the Practice of Medicine: Beyond Pills and the Scalpel,* Yale University Press, New Haven, p158.

Their injuries or diseases become the source of the potency of their stories. Through their stories they create empathic bonds between themselves and their listeners. However, seriously ill people are wounded also in voice. They need to recover the voice that their illness in effect takes away. The voice speaks the mind and expresses the spirit, but it is also a physical organ of the body. The mystery of illness stories is their expression of the body; 'in the silences between the words, the tissues speak.'[588] What we reveal through silence or story is the deepest level of the self.

The philosopher Hilde Lindemann Nelson argues that being fully human requires 'the ability to reveal through [one's] actions who [one] is as a person,' a revelation she calls 'normative self-disclosure.'[589] For her moments of normative self-disclosure are moral moments. In these moments like it or not, *what we do reveals who we are*; the values we uphold and how well we hold them up becomes evident to ourselves and to others. As we see others react to this self-disclosure, we come to know ourselves. Normative self-disclosure thus requires dialogue; the person who we see ourselves revealed to be is seen most fully in others' responses to us. However, self-disclosure that dialogue makes possible can be impeded when some people refuse to accept others as partners in dialogue.

Principal among damaging conditions is others' unwillingness to hear stories in which storytellers place their actions within worthy, significant moral frameworks, treating others' actions as indicative of a less than fully mature human consciousness. Those treated in this way Nelson suggests develop an 'oppressive identity' - that is they are oppressed because their identity is rendered oppressive to them.[590] They are finalised. Thus they are humiliated before they have acted - before the story has begun, because they have internalised other people's stories about who they can and cannot be. Medical patients acquire oppressive identities when others cut off their telling of stories. In these stories people living disrupted lives seek to place their experience within significant moral frameworks.

As the philosopher Charles Taylor remarks:

> Our identity is partly shaped by recognition, or its absence, often by *mis*recognition of others, so that the person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them a confining or

[588] Charon, R., (2006) Ch. 9
[589] Nelson, H L., (2001) *Damaged Identities, Narrative Repair*, Cornell University Press, New York, p25.
[590] Nelson, H L., (2001) p25

> demeaning or contemptible picture of themselves. Non-recognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted and reduced mode of being.[591]

Jodi Halpern, a physician, believes that the primary question lies in how not to think with the other's story, it is how to think with your own story. The other's story is merely the trigger for an ethics of reflexive monitoring for both patient and physician.[592] Thus the moral moment occurs when we who imagine ourselves as a single cognisant judging 'I' must decide whether to give equal weight to the other cognisant 'Is' around us. We acknowledge, or not, that the very possibility of our self and thoughts has always depended on others. And thus we enter into dialogue or not.

Without dialogue however, Bakhtin suggests:

> [Dialogue] is not the means for revealing, for bringing to the surface the already ready-made character of a person; no, in dialogue a person not only shows himself outwardly, but he becomes for the first time that which he is - and, we repeat not only for others but for himself as well. To be means to communication dialogically. When dialogue ends, everything comes to an end. Thus dialogue by its very essence, cannot and must not come to an end.[593]

A medical moral moment inhibited by cutting off dialogue renders both the patient and the physician unheard, unrecognised and unremembered. Escape from dialogue is also critically an escape from oneself with a consequent hiatus in the process of healing. A physician's responsibility therefore is not only to diagnose and treat patients' diseases but also to witness patients' attempts to understand themselves as morally responsible despite their dependence. Narrative ethics cannot offer people clear guidelines or principles for making decisions as a result. Instead what is offered is permission to allow the story to lead in certain directions - without prescription.[594] Speaking *about* and speaking *with* is what many physicians fail to truly understand. Testifying to illness as a communicative body may be an individual moral choice, but this testimony implicates a wider social ethic.[595]

Due caution must be exercised in doctor/patient relationships however. Medicine and therapeutic work generally are especially at risk of committing symbolic violence because professionals in these fields speak with an authority deriving both from their expertise and

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[591] Taylor, C., (1994) *Multiculturalism*, Gutmann, A., (ed.) Princetown University Press, Princetown, p25.
[592] Halpern, J., (2012) Empathy: Using Resonance Emotions in the Service of Curiosity in Spiro et al *Empathy and the Practice of Medicine: Beyond Pills and the Scalpel*.
[593] Bakhtin, M M., (1984) p252
[594] Frank, A W., (2013) p160
[595] Frank, A W., (2004) pp45-47

their claim to be acting in the patients' best interest. People come to doctors because they want their medical problem made better, cured or improved - they seek this type of authority. It becomes all too easy for professionals to forget that authority is two-way and patients also want to be respected for who they already are. For doctors it is easy to see the patient's need or lack, move to some remedy or solution and miss their 'face.'[596]

For Levinas, the basis of dialogue is a relationship of otherness, sufficient difference and distance so that there can be space between two. Levinas refers to this distance as non-contingent otherness or alterity.[597] Alterity does not depend on contingency or any agreement of when and where someone is born or what life choices she makes. Alterity is an intrinsic quality of being human. It precedes such specific differences:

> It is not because your hair is unlike mine or because you occupy another place than me - this would only be a difference of properties or of dispositions in space a difference of attributes. But before any attribute, you are other than I, other otherwise, absolutely other! And it is this alterity, different from the one which is linked to attributes, that is your alterity.[598]

Levinas believes that to infringe on the other person's alterity is to commit violence against the other. Symbolic violence comprises the often subtle ways that alterity is challenged. Such violence claims to object to specific choices and decisions, but the objection shifts from the choice to the person choosing. It is the violence of telling people that they should not be who they are, or that they fail to understand who they ought to be.

Levinas's ethic begins with seeing the *face* of the other - the other's vulnerability and weakness. Seeing the face often begins with the empathic imagination of how the other feels, but empathy risks the symbolic violence of telling the other how to feel better. Alterity as such is not opposed to empathy or to feeling better for that matter, but empathy as an end in itself can be dangerous to alterity. Empathy tends towards unification: either my projecting what would make me feel better onto you, or my fusing with your suffering. Alterity is the opposite of unification with the other. Seeing the *face* of the other requires respect for alterity: a recognition that there are aspects of your suffering that can never be imagined or touched. It is that difference which makes dialogue possible, however it is also what makes dialogue difficult, simply because the other *is* the other. Emotional pain is one such instance for it is a pain that frequently exceeds any physical suffering, making it difficult

[596] Levinas, E., (2001) *Is It Righteous to Be? Interviews with Emmanuel Levinas*, Robbins, J., (ed.) Stanford University Press, Stanford, p49.
[597] Levinas, E., (2001) p49
[598] Levinas, E., (2001) p49

for a patient to express their needs. The patients' emotional pain is what sets them apart because in fact they *are* apart.[599]

Like Levinas, Frank, believes that within a medical setting alterity with its demand for specification and explanation risks finalising discourse and thereby closing it down. To specify a person's alterity is to assimilate them into a unifying voice that claims to explain them. In the unity of that explanation there is no space for unexplained difference: so difference - along with the patient - evaporates, and therefore is explained away. Alterity is not ineffable - it is not that of which it is impossible to speak. Alterity turns into symbolic violence of finalising the other when it reduces personhood to some set of inherent properties that explains the patient as a problem and why that problem could not be solved.[600] Human moral essence is people's acute 'sense of their own inner unfinalizability', their capacity to outgrow from within and to render *untrue* any finalising definition of them.[601] The significance of care and compassion that leads to identification with the ill and disabled, respects this capacity to outgrow especially when the potential for growth can seem limited. Speaking *with* a patient not about them, entering that space between the patient and medical professional in which both remain other, but in which each offer themselves to be changed by the other, is a sounder basis for a considered approach to caring.

Medicine and the ethics of care

Richard Zaner's observation of individuality in patient care substantiates the thesis that due caution should be paid to an ethics of care model created either along utilitarian or deontological criteria that would once more lead to a static framework and remove the important focus on the individual. And equally a model that is in danger of echoing the perceived problems associated within the Principlist bioethical framework devised by Beauchamp and Childress. The fluid, porous nature of humanity that is the theme of this thesis demands an approach commensurate with a wholistic interpretation of life.
Zaner explains:

> Wanting to know and wanting to be cared for are thus special appeals through which the person seeks recognition, affirmation and appreciation of this singular

[599] For a detailed explanation of what alterity means in clinical practice, see Paul Komesaroff: The Many Faces of the Clinic in Toombs, S K., (2001) pp317-330. Emotional pain I see as suffering.
[600] Frank A W., (2004) pp116-117
[601] Bakhtin, M M., (1986) p138

> person she is or hopes to be. *To want to be cared for, in this deeply personal sense, is to want fundamentally to be this self in the presence of those who take care of her precisely in her vulnerability and suffering.*[602]

John Reeder believes that care begins in the love of particular persons.[603] Goods and evils are not necessarily allocated within a utilitarian sense of impartiality, since choice can intervene. If the metarule 'do no harm' is brought into play it does not necessarily follow that bias is ruled out. Thus care may be partial, weighing the good of some more than others, yet still aiming within these parameters to do the most good or least harm for those affected. For Reeder care has its own reasons. Love for one's country can sometimes conflict with love for family, for example.[604] Perhaps it is better to say that various constitutions of care have different distributive remits. To understand what is happening *we have to look and see and also listen and hear*.

Caring involves a firm disposition to account for the unique position of the patient in receipt of such care. It is similar to though distinct from the value of beneficence. Both involve a focus on advancing the 'good' of the patient. A good ascertained by the involvement in the care process of the patient's story. However beneficence can be a detached paternalistic value. A beneficent health care provider may strive to make a rational, objective decision about what is best for the patient or for those similarly situated medically. In contrast an ethic of care stresses that a caring response is determined for each unique patient within that patient's particular network of relationships and given their unique needs and desires. The response is 'tailor-made', customised.

Careful sorting out of personal experience, partly through the construction of a narrative of that experience, is a means to better understanding the moral dimensions of medical care. According to Ruth Smith when responding and listening are understood to be key to bioethics, ethics itself is re-formed as an activity that is always located, always linguistically structured in particular ways and always in flux.[605] Space and location are significant for they influence the manner in which moral action takes place. As an experience of the senses,

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[602] Zaner, R M., (1994) Experience and Moral Life: A Phenomenological Approach to Bioethics in *A Matter of Principles: Ferment in US Bioethics*, DuBose, E R., Hamel, R P., and O'Connell, L J., (eds.), Trinity Press International, Valley Forge, Pennsylvania, pp211-239. My italics.
[603] Reeder, J P., Jnr., (2001) Are Care and Justice Distinct Virtues? in Cates, D F., and Lauritzen, P., (eds.) *Medicine and the Ethics of Care*, Georgetown University Press, Washington, pp10-11.
[604] Reeder, J P., Jnr., (2001) pp10-11
[605] Smith, R L., (2001) AIDS in East Tennessee: Medicine and Morals as Local Activities in Cates, D F., and Lauritzen, P., (eds.) *Medicine and the Ethics of Care*, Georgetown University Press, Washington, p298.

place tells us 'where we are equivocally and unequivocally as we make our way around.'[606] Place reaches out for the senses that extend further experiences of association, memory images with their familiarity and shock aspects 'that may or may not take on the shape of narrative with a beginning, middle or end'. The point here is that spaces considered outside of the medical arena are morally significant for both medicine and ethics since spaces actively reconfigure in varying ways moral notions of self, knowledge, action and place entailed in any one instance of events that happen to occur or not. Every moment of decision never stands alone; it is invaded by all others that brought people to a place they find themselves in that moment. Thus the influence of multi-vocality cannot be underestimated. Morality shifts and turns and re-forms elsewhere, immediately moving us on to where we have never been before, to a place that was not even a 'where' before that moment. Medical ethics is not the scene of the application of thought, medical ethics is an *activity* that cannot be identified with one kind of person, one kind of speech and one kind of space, because such identifications produce ethical criteria that may work to the detriment of patients as part of the 'good' being done.[607] The question is how to work with what is going on for the patient. The question that haunts every day of extended illness and raises every kind of question of living and dying is a territory much too large and bumpy to be limited to the practices that have dominated much of medical ethics and moreover ethics itself.

Smith argues for a messier, more complex view that is not summarised by a principle or rule. For her ethics is highlighted by such human characteristics which involve saying, being or doing, that indicate the uncertain character of moral landscapes and discourses and the place of morality in action.[608] Ethics is slippery and thereby traditional moral codes are called into question as an adequate way of describing moral activity in situations in which so much is unknown. Margaret Walker elaborates the idea of context through narrative, arguing that ethicists who work in healthcare are better understood as architects of moral space than as masters of normative law and code.[609] As a participant in a narrative, the ethicist helps design a way for things to happen through negotiation and mediation in the conversational space where different people meet. Looking out for moral interaction takes place not apart from but amidst the process of design.

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[606] Smith, R L., (2001) p303
[607] Smith, R L., (2001) p312
[608] Smith, R L., (2001) p298
[609] Walker, M U., (1993) Keeping Moral Space Open: New Images of Ethics Consulting in *Hasting Center Report* **23:2:40**

Diana Cates and Paul Lauritzen believe that focussed attention itself reliant on an acute engagement with affective influences is not only fundamental to care but also to mutuality.[610] Within the context of mutual care individuals are best able to reflect on their moral responsibilities toward others when in touch with their own emotions, and are able to discern what should be done for others on their behalf. For Noddings an ethic of care is motivated by an emotion-laden need to 'remain in the caring relation and to enhance the ideal of ourselves as one-caring.'[611] By contrast Andolsen[612] in agreement with Pellegrino[613] asserts that medical professionals have a duty to provide competent care that flows directly from their claim as professionals to have mastered a unique body of professional knowledge. Such an understanding however is not encompassing enough. Surely the moral *ideal* of caring integrates positive emotions with a commitment to care that results in caring actions. The ideal of caring is of professionals who convey generous, compassionate and warm concern for patients who are entrusted to their care.

On the other hand, care also challenges ethics to assess realistically the ambiguity of caring as a positive affective state. Caring requires taking into account issues with 'difficult' patients. We hear frequently in the press of ambulance personnel and emergency unit doctors and nurses being attacked. Thus there seems to be a complex relationship between morally admirable caring and positive affective states. It is too simplistic to suggest that professionals have somehow failed to fulfil their moral duty if that so-called 'warm-response' is not forthcoming. Noddings argues that it is the prior recognition of the other as worthy of care and a firm commitment to act in order to promote the good of the one cared for that are particularly important in an ethic of care. She maintains that one of the most important experiences in human life is the experience of being cared for in a loving way. Her depiction of the moral agent naturally attracted to the ideal of the self as a caring person fits closely with the professional and social *ideal* of the medical profession.[614] And Helga Kuhse proposes 'caring … is not primarily concerned with tasks and processes, but is a mode of being …a stance or attitude towards the object of one's attention.'[615]

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[610] Cates, D F., and Lauritzen, P., (2001) (eds.) *Medicine and the Ethics of Care*, Georgetown University Press, Washington, p xvi.
[611] Noddings, N., (1984) Caring: *A Feminine Approach to Ethics and Moral Education*, University of California Press, p5.
[612] Andolsen, B H., (1993) Justice, Gender and the Frail elderly: Re-examining the Ethic of Care. *Journal of Feminist Studies of Religion,* **9:1/2:134-137**
[613] Pellegrino, E D., (1989) The Primacy of the Act of Profession in *Ethical Issues in the Professions*, Windt, P Y., et al (eds.) Prentice-Hall, New Jersey, pp 76-84.
[614] Noddings, N., (1984) p28
[615] Kuhse, H., (1997) *Caring, Nurses, Women and Ethics*, Blackwell, Oxford, p147.

Compassion

Abraham Verghese's account of ethics is not to establish a backdrop for moral action but to explore and analyse how players transact situations of medical ethics at the stage of disease.[616] Thus morality would include activities that expand moral traits to include respect and compassion together with assistance and courage, resistance and solidarity. For Carter Heyward com-passion is a way of being in touch with others, a way of being connected; it is our passion *with* one another. Compassion is a gift of our genuine involvement in one another's lives. 'It is a radically relational blessing' in which we realise that our own best interests and those of others coincide.[617] The root of compassion is humility. And if our humility is real, it is our embodied knowledge that our lives are connected and that no one of us is more or less human, greater or smaller than another. Humility engenders empathy and tenderness among us and makes possible our emergence as compassionate people. The public shape of our compassion is solidarity - standing with those who suffer. We do not tell them what's best for them, nor expect them to know what's best for them; we stand with them in mutual relation, trusting that each has something valuable to contribute to all and that in mutual relation, their wellbeing and ours are inextricably linked. It is at its most pure. It is an open invitation into right relation.[618] Mutuality is our shared experience of power in relation. By it we are called more fully into becoming who we are - whole persons with integrity, together. 'It is a calling forth, an occasion to touch each other's lives, and an open invitation into the healing of common woundedness.'[619] Loving is difficult however because learning to share our com-passion requires from us 'revolutionary patience' with one another, not renunciation of ourselves or others. It takes a great deal of time and love for us to learn how to let go of our senses of separateness, isolation and self-control and risk not only reaching out to touch others but allowing ourselves to be touched deeply by them.[620]

In hospitals, at the bedside where it counts, a health care system is people touching each other. Everyone who touches anyone affects that person's healing and affects the further demoralisation of medicine - or it remoralisation. In the moral moment of that touch, there is no system. Care can only be a relationship, a dialogue that may not only be of words but

[616] Verghese, A., (1994) *My Own Country: A Doctor's Story*, Vintage Books, New York, p137.
[617] Heyward, C., (1989) pp140-142
[618] Heyward, C., (1989) pp140-142
[619] Heyward, C., (1989) pp99-100
[620] Heyward, C., (1989) pp99-100

of touch. As one technician has put it 'remember, everyone who touches you affects your healing.'[621] Touching and being touched is fundamental to human being. According to Frank in a clinical setting a life has been touched in so many ways and often by people who seemed indifferent to patients' healing.[622]

Elizabeth Wolgast asserts that modern organisational life has proliferated a style of being human that transforms a moral relationship into an administrative problem. The responsibility of professionals is thus to carry out policies and to that end they are encouraged not to worry whether they 'injure their moral souls' by acting as they are called to act.[623] In this vein, care can denote a quantity of services expended not a moral response of one person to another. It becomes an allocation, increasingly determined by forms of management. Care derives from the state, professional and private corporate organisations that reach into clinics and hospital rooms through multiple avenues. As Wolgast states: 'Moral ambiguity…stems in part from the fact that those receiving the orders are in the circumstances of action while those issuing them stay at a distance.'[624] The nurse or physician is face to face with the patients, while those determining conditions of treatment remain at a distance. The orders include how much time can be spent with a patient, which patients will be referred to specialists and how long they will wait for appointments. In these or other matters the nurse or physician is required to be an artificial person, speaking in the name of management. Yet professional and personal ethics require responding to this face before them, accepting the obligation the face demands. The key is to understand that the needs of the patient must be balanced against the good of the community of patients *without losing sight of the face of each individual*. In 2017 with ever increasing costs in the NHS and ever-decreasing time and resources this is a tall order. Medicine today comprises an unthinkably broad array of knowledge and skills, professions, coalitions and interest groups, fears and promises, fantasies and soon-to-be realities, concrete and virtual institutions. Parts of this array enter people's awareness and other parts affect them outside of that awareness. The context if medicine is to have any meaning at all is crucial. Stories effect and are affected completely by these contexts.

[621] Frank A W., (2004) p27
[622] Frank A W., (2004) p27
[623] Wolgast, E., (1992) *Ethics of an Artificial Person: Lost Responsibility in Professions and Organizations*, Stanford University Press, Stanford, p3.
[624] Wolgast, E., (1992) p32

Communities of care

This, then, is the basic pattern of caring, understood as helping the other grow: I experience the other as an extension of myself and also as independent and with the need to grow; I experience the other's development as bound up with my own sense of well-being; and I feel needed by it for that growing. I respond affirmatively and with devotion to the other's need, guided by the direction of its growth.[625]

Milton Mayeroff

The training of doctors to listen and read signs of suffering beyond the medical symptoms is vital to patient outcomes. Evidence has shown that the patient's own understanding of the meaning of their illness interpreted through narrative is significant in activating the process of healing. Furthermore long-term, patient prognosis has the potential to be far more positive and far less pressing on time and financial constraints that have continued to trouble medical professionals and institutions well into the twenty-first century. In short although consultants would benefit from hearing patient stories to underpin their decision-making, they are afforded little time to engage in lengthy patient appointments that are not considered directly salient to the medical case. Management of narrative if it is to be both useful for the medical professional and significant for patients' continued wellbeing requires alternative means by which meaningful patient input may be included to enhance and make more robust the decisions taken which will deeply affect the rest of their lives.[626]

Recipients and donors are assailed by a diverse range of highly technical information that potentially is bewildering at the very least and possibly frightening at difficult moments in the donation/transplantation process. Tests for both donor and recipient extend for about a year according to NHSBT and the mean time for kidneys is just over two years before transplant takes place.[627] What happens in the intervening period is of significance for future prognosis. Patients die while on the transplant/organ waiting list.[628] Suitable organs are not always forthcoming for various medical reasons even when available, thus recipients are sent home and expected to 'wait for the phone to ring' with little guarantee of a transplant after a possible protracted length of time. It is equally not unusual for this situation to occur more than once. Relatives all too often have to 'pick up the pieces' after many a disappointment and maintain a positive supportive and hopeful outlook throughout the waiting period. It would seem important therefore that some further medical support

[625] Mayeroff, M., (1971) *On Caring*, Harper Collins, New York, pp11-12.
[626] For both patients and medical professionals.
[627] See Ch.3 p65 of this study.
[628] 470 people - both adult and paediatric died in the period 1st April 2016 - 31st March 2017. See NHSBT Activity Report 2016-2017. www.nhsbt.nhs.uk accessed 20/05/2017.

through this 'agonising' wait would not only be appropriate but also fundamental in reassurance and the kindling of hope and faith that things can turn out as anticipated for those concerned.

Healing as becoming or being made whole again is a much larger and more complex concern than we ordinarily assume when we think of such sharply delineated therapies as medication or surgery. Much of this often-ignored complexity consists in the understanding that many of the ways we foster healing are communal in nature. For those communities integral to the healing enterprise, trust is crucial. The threat to the patient's integrity in illness is diffuse, giving rise to vulnerability on several levels and the possibility of the loss of self. Zaner captures this point when he writes

> With these telling glimpses of loss and death, illness confronts the person with what and who she is, was and hopes to be, with finality. Wanting to know and wanting to be cared for are thus special appeals through which the person seeks recognition, affirmation and appreciation of this singular person she is or hopes to be. To want to be cared for in this deeply personal sense, is to want fundamentally to be this self in the presence of those who take care of her precisely in her vulnerability and suffering.[629]

Even when a condition cannot be fully restored and life becomes a different kind of 'normal', importance is attached to the greatest possibility to resume or sustain prior roles and relationships, restricted minimally by bodily dysfunction or discomfort. The broader view of healing as regaining wholeness puts into larger context the patient's dis-ease, when other dimensions of the patient's situation are accounted for, prompting professionals to consider the fuller significance of the patient's particular problem.

Thus care as in caring for someone refers on the most basic level to being well disposed toward the one-cared for and provision of the means to carry out that caring. As most commentators have argued, there is an attitudinal and affective dimension supported by action to caring. Paul Camenisch believes one further dimension - the modal dimension - to be equally important. It refers to the manner in which professionals carry out their activities: on the one hand with due attention, precision and deliberation - that is carefully - or on the other casually, indifferently and perfunctorily - in other words care-lessly.[630]

[629] Zaner, R., (1994) pp211-239

[630] Camenisch, P F., (2001) Communities of Care, of Trust and of Healing in *Medicine and the Ethics of Care*, Cates, D F., & Lauritzen, P., (eds.), Georgetown University Press, Washington, p238.

Primary amongst those who have the potential to transform the sick, vulnerable and often lonely, into a comforted, well cared for and already healing person are often the various people, besides the medical professionals, who drop by to offer support and caring at the greatest time of need. Each bring a very individual and personal form of care that grows out of the carer's identity and style and out of the relationship between the patient and the visitor. Members of the community in which the patient is involved such as church, family and friends, serve to maintain the vital link to the community when sickness renders the patient alone and feeling isolated. As Camenisch argues an association of people who are like-minded and share functional interconnections share commitments to each other and to certain valued tasks and goals, values that make community members who they are as personal, moral and even spiritual beings.[631]

Although patients primarily look to technical care from the medical professional community, it is from the personal communities that the wider variety of needs is frequently addressed. Visits, the sending of cards, support for the family of the patient, together become the very important anchor that the patient needs to maintain their identity *as the person they are* and significantly to engender levels of trust, despite the havoc that illness has wrought upon them. In recalling the possibility of the connection between wholeness and health, potentially the patient who is experiencing a threatening situation who can truly trust her care-givers, I argue, has already achieved a kind of wholeness, including a realistic acknowledgement of the illness state. Equally an assessment of her resources and options confirmed through dialogue and narrative, fosters a cohesiveness of self despite the fragmentation illness brings, and gives rise to the patient's permission to place herself trustingly in the hands of others. Camenisch agrees that the patient 'riven with doubts and uncertainties…and pulled in various directions simultaneously by competing hopes and fears, obviously suffers from a lack of wholeness at some level.'[632]

Charon terms extended patterns of relationships 'communities of care'. Multi-vocality as suggested by Frank[633] and de la Bellacasa[634] are pivotal in deepening care relationships that are necessary for the patient to continue the healing process long after hospitalised medical treatment has stopped. Interestingly many hospitalised patients themselves gather together those close to them locally - relatives, friends, doctors and nurses they trust and so on to

[631] Camenisch P F., (2001) p247
[632] Camenisch P F., (2001) p247
[633] See Ch.5 of this study - Alternative ethical approaches.
[634] De la Bellacasa, M P., (2017)

form their own support groups, even where none exists formally.[635] Communities of care have proven invaluable over the years in many different organisations to the benefit of those in particular experiencing the lengthy process of donation and transplantation both pre- and post-surgery. Valuable stories telling the deeply felt experiences of all concerned are useful emotional support. Through access to authentic patient stories, medical professionals stand to gain from a deeper understanding of the experiences of those involved in accessing their care. Potentially change in treatment protocols will be created in such a way as to progress skills that will 'hold out the promise of a set of solutions to the hobbling isolation and divisions that currently plague and weaken medicine.'[636]

However, illness or disability poses a threat to moral participation in the world. People who are ill or disabled have problems staying in 'networks of participation' and participating on terms that are meaningful to them and are recognised as meaningful by others. The body in trouble causes patients to be fearful. Nancy Mairs, a sufferer of multiple sclerosis observes this fear as '[having] visions of enduring life at the hands of strangers; refused food or drink, shoved roughly into bed, allowed to slip from my wheelchair and abandoned in a puddle of my own urine.'[637] Her fears however extend beyond the risks of institutionalisation. The body is the vehicle for dialogical engagement with others and as it becomes more troubled, the very same moral paralysis that is her deepest fear is realised. A friend of mine who underwent a total liver transplant (a very rare procedure) admitted that on waking after transplant surgery, cried because he realised he had survived such a serious procedure. But subsequently was disheartened to learn that he had become diabetic. At the same time he confessed that he would have loved to sit down with his doctors and discuss what 'having someone else's liver in my body means to me.'[638] We need to ask deeper questions about the longer-term benefits of listening to patient stories.

Mairs places care 'at the heart of moral experience' equating 'downward' care with failure to recognise the person being cared for as a moral presence, not a body in which the human is currently absent. 'Beyond cheerfulness and patience, people don't generally expect much of a cripple's character. And certainly they presume that care, which I have placed at the heart of moral experience, flows in one direction, "downward": as from adult to child, so from well

[635] Camenisch, P F., (2001) pp234-269
[636] Charon, R., (2006) p198
[637] Mairs, N., (1966) *Waist-High in the World: A Life among the Nondisabled*, Beacon Press, Boston, USA p56.
[638] Confidentiality prevents stating a name, but permission to relate this story was given.

to ill, from whole to maimed.'[639] The asymmetry that is inherent in much medical care means that care cannot be mutual in a material sense, but each party to a relation of care can imagine the other as having something to contribute to the needs of the world. Bridging the gap between understanding patient needs for caring and compassion and praxis, requires moving forward in a different way for there to be any progress in putting the patient at the forefront of the medical enterprise - there needs to be a paradigm shift in the nature of how medical care is managed.[640]

Institutional medicine provides multiple alibis for not entering into relations of care. There are it seems many *good* reasons for truncating care, for circumventing or indeed finalising other people. All these reasons are real in the sense that they reflect the actual demands of medical practice. But these reasons are also unreal because in the interpersonal moment of practising medicine anyone can act differently. The real question is whether any of the reasons for truncating or circumventing care are *good* reasons. Do they create a medical practice that can be a template for the relations of care we want to prevail in a moral society? Do they reflect rather medicine's treatment of its patients as what Martin Heidegger describes as 'objects on call for inspection, subordinates to the orderability of the clinic?'[641] Stephen Lammers calls for teaching the patient something about the limits of medicine as a discipline believing that a moral agenda should begin where medicine stops.[642] Care should go beyond eradicating disease to caring about what sort of moral person a patient will become through their own experience of disease to enable patients to think beyond the person they have been.

Evidence has shown that illness is a thick concept that includes the different social, cultural, communal and often psychological repercussions of the disease, and the ways the patient and their various communities perceive and respond to those dimensions of the patient's situation. As discussed in Chapters 5 and 6 contemporary highly-tech medicine and moreover practitioners, have become so influential in the choice and delivery of the care required that 'the rest of us feel like untutored and largely helpless lay-people…while the real action occurs in the surgical suite or other highly specialized, even exotic settings.'[643]

[639] Mairs, N., (1996) p62
[640] Discussed at the beginning of Ch.6 of this study.
[641] Quote in Frank A W., (2004) p28
[642] Lammers, S E., (1996) p31
[643] Camenisch P F., (2001) p249

Yet accounts of traditional healings show that community involvement in care and support are crucial to the patient returning to the community whole.[644]

Current communities of care such as transplantation groups generally set up and run through specialist hospitals are clearly an important source of information and support for patients and their relatives pre- and post-surgery, so too is the team of transplant co-ordinators.[645] Being patient led in many cases, these support groups have a significant role to play in dispelling some of the fears and fantasies that frequently accompany patients throughout their illness. Critically patients have opportunities to be given time, to be listened to and reassured at stages when they feel the most ill at ease. The sharing of information informally in a group of like-minded people, some of whom may have extended experience of the effects of transplantation medicine in allaying fears, may prove to lower costs and result in greater efficiency in outcomes in the long run, reducing the time for instance before a further transplant becomes necessary.[646]

However, further questions need to be raised concerning the impact of siting communities of care within hospital environments. According to Smith, place and context participate in and exercise considerable influence on the manner in which morality is implemented.[647] A predisposition to denote space as a determining category that controls fundamental conditions of existence and meaning is a tendency in working practice within institutions especially within medical organisations. A further inclination is to consider place as a determining category of the inertia within which no motion/change is possible. Both of which naturally run counter to the understanding that bodies, be they organisations or human are dynamic, fluid and porous in essence, whether this is understood or not. Any ethical framework is bound by such practices that inevitably will result in a limited view of the position of individual caring and the benefits that might accrue from a change of perspective.

The place of context is problematic. In supporting narrative theorists Frank and Charon, Smith argues that accounts of context are accounts of relations and so are active and not

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[644] Covington, D., (1985) *Salvation on Sand Mountain: Snake Handling and Redemption in Southern Appalachia*, Penguin, New York, and Knab, T J., (1995) *A War of Witches: A Journey into the Underworld of the Contemporary Aztecs*, Westview Press, Boulder, Colorado.

[645] See the major transplant specialist hospitals Addenbrookes at www.alta.org.uk Royal Free at www.royalfree.nhs.uk/services, see other support groups at www.pscssupport.org.uk/support-groups-transplant-units

[646] Life expectancy of a transplanted kidney is between 5 and 10 years, and timeframes for hearts are considerably shorter see NHSBT annual reports for latest figures.

[647] Smith R., (2001) pp298-301

passive. They do not simply describe but attempt to persuade in terms of what merits acknowledgement and what does not. Any notion that context is prior to morality she maintains suppresses moral arguments and perspectives that are themselves only available through considerations of the context in which they are debated.[648] What passes for an appropriate narrative within transplant medicine has already been demonstrated by the variety of sanitised patient accounts of the successful outcomes of their procedure. The marketing of such accounts through hospital and NHS websites are placed solely to 'advertise for' organ donation in the hope of increasing organ supply. More interesting however is the annual British Transplant Games involving living donors and transplant recipients that are run explicitly to demonstrate 'the benefits of transplantation whilst increasing public awareness of the need for more people to join the NHS Organ Donation Register and discuss wishes with their families along with bringing together the transplant community to celebrate the gift of life.'[649] Furthermore, each year Organ Donation Week is run as a marketing exercise to recruit donors.[650] It's a mixed bag of initiatives that hitherto has not produced anything like the increase that will unseat the long-held ratio that *for every patient* who has a transplant *three* patients die on the waiting list.

Hospitals have become businesses with all that entails - effectiveness and efficiency in terms of finance and working practices therefore override the original caring intentions of medically associated organisations. Organ transplantation is a 'gold standard' procedure and amongst the most expensive of treatments offered by hospitals specialising in such surgery and long-term care.[651] It is surely time to consider how patients understand and communicate how their illness has transformed them as people by helping them to begin the process of taking responsibility for their own continued wellbeing. Narrative has been proposed as a way forward for improved prognoses in the alleviation of suffering and its influence on healing illness and dis-ease. Taking responsibility for personal health and wellbeing and lessening the time spent in doctors' surgeries and hospitals is advancing at a pace with modern technological devices installed in the home. Such progress will change the face of ethics as the blurring of the boundaries between technology and the body becomes

[648] Smith R., (2001) pp298-299
[649] See www.britishtransplant games.co.uk accessed 28/7/2017 (The games were set up in 1978 originally as an international event).
[650] For 2017 the strapline: 'Let's Talk About It' promoted the campaign to talk about donation within the family to confirm permission to donate after death especially in cases where no other permission is known to be authorised as in a will for example.
[651] Sharp, L A., (2014)

increasingly prevalent.[652] Now more than ever support for each other in circumstances of chronic ill health is paramount.

Conclusions

It is important that doctors identify with their patients. Time to listen and not finalise the patient in her attempt however haltingly to represent her illness as she sees it and think things through beyond the 'norm' of treatment protocols to reach into the needs of the patient have been shown to be paramount to recovery. Such action restores faith and hope in the realisation that we are multiple beings, that to treat a diseased part of the body only is to ignore the impact on the rest of it. That dialogue, listening, hearing, looking and seeing are infinitely more complex than a case history can ever represent. It would benefit patients greatly when voices are heard of those faced with a long wait for an organ, or those who have received the prognosis of a grim outcome to their illness. They may be assisted with suitable treatment and care if all the facts are known across the medical team involved so that their lives may be as purposeful as possible within the limits of their illness, even in the event that nothing can be done for them. Patient input is not only beneficial to their progress and understanding but also to others who find themselves in a similar position, and to those responsible for their care. More importantly if multi-vocality is to have any power in progressing and delivering change within bioethics, it is right that the wider community involved is given the opportunity to voice their individual approval or concerns. As stated in Chapter 3, bioethical perspective underpins the law that has far-reaching consequences for us all. With advancing technology and the merging of the body with both human and synthetic prosthetic parts, the urgency of examining progress in this area becomes crucial. As Gawande suggests 'I'm more and more convinced that the power's going to come from how human beings and automation come together.'[653] Who will assume responsibility when things go wrong? The discussion in Chapter 8 now turns to reflect speculatively on how the value and definition of the body will be transformed by the continuing relationship between and assimilation of humanity and advanced technology and how care might be integrated into aspects of human and non-human life in the twenty-first century and beyond.

[652] See Ch.8 p197 of this study.
[653] Gawande, A., (2014) The Reith Lectures No.2.

Chapter 8

Posthuman Bodies -

A speculative glance at the future of bioethics

Introduction

This chapter turns full circle to the notion of the body discussed in earlier chapters and addresses the central issue of how the process of the fusion of technology with the body and its functioning will have impact on future bioethical approaches. The discussion is positioned here not only because it encapsulates the ideas put forward in the Introduction and Background, but one glance at the Timeline in the Appendix shows just how far behind legal and ethical matters lag in contrast with technological progress. With today's rapid technological advances, bioethics and the law surely need at least to keep pace. Thus it is both timely and vital to consider potential issues and future options for progressing alternative bioethical approaches. Concepts including the nature and status of living matter; the fusion of the body with technology and non-human parts; the positives and negatives of biotechnological development; hybridity and the blurring of ethical boundaries and notions of the types of care proper within a posthuman setting are presented as potential areas for critical thought.

We are moving rapidly towards the merging of our ways of life with science and technology that inevitably will require a different perspective on human being or indeed becoming. It will involve us in myriad ways, whether we are sick or healthy, primarily in reshaping the meaning of humanity. The discussion in this chapter therefore considers the idea of the posthuman as a metaphor for progression towards the development of any ethical input concerning the body and the nature of being in general and within the medical profession in particular. Such contemplation, albeit speculative (for we are not there yet) is timely, since a glance at the Timeline in the Appendices reveals just how far behind Acts concerning bodily matter become written into law in comparison with biotechnical progress.

Devising new social, ethical and discursive schemes of subject formation to match the profound transformations of technology we are undergoing will become increasingly pressing. Biotechnological advances potentially will change the form, function and meaning of the body in diverse ways with the result that learning to think differently about ourselves could be challenging. In other words increasingly we will need to think critically and creatively about how we wish humanity to be seen in terms of *who and what we are* actually in the process of becoming. Braidotti makes the point that the posthuman predicament rather than seen as a negative step is an opportunity to empower the pursuit of alternative patterns of thought, knowledge and self-representation of the body.[654]

In turning to a central theme in this study, it is noteworthy that remarkable advances have been made in transplantation procedures over the last fifty years including: technology to keep solid organs more stable pre-surgery; elective ventilation; maintaining blood flow and control of the temperature of hearts pre-transplant for improved organ assimilation; the use of 3D printers for body parts and progress in keyhole surgery for faster and greater success in recovery for both donor and transplant recipients.[655] The use of pigs and sheep to grow kidneys for human transplant, in the hope of lessening the impact of a shortage of organs for transplant for instance, is estimated to be available in 2019/2020.[656] These advances certainly raise significant normative questions.

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[654] Braidotti, R., (2013) *The Posthuman*, Polity Press, Cambridge, p12.

[655] A Chinese surgeon has replaced five consecutive vertebrae in a patient's neck with a 3D prosthetic in the first operation of its kind, reported in The Times 11th August 2017 article: Patient given 3D-printed spine after tumour attacks neck bones.

[656] The Times 11th August 2017 article: Pig-to-human transplants 'are two years away', www.thetimes.co.uk/article/pig-to-human-organ-transplant-two-years-away accessed on 11/08/2017.

Gene splitting, mitochondrial splicing and stem cell interventions are the focus of continuing research projects and medical usage. Indeed further progressive techniques are already possible but not yet harnessed, the use of advanced neural network techniques in robotics for complex decision-making is one such example.[657] Robots are already used in industries such as car manufacture to provide car body parts more accurately and efficiently in a cost saving exercise that replaces sections of the workforce. Moreover a number of organisations are implanting chips in the wrists of their employees in order for them to gain access to various items of equipment: to open security doors, log into printing equipment; log into sensitive data and so on.[658] And even more mind-boggling - fast food in China can be paid for through face recognition, with just a smile.[659] In short the use of digital and advanced forms of technology is intimately connected to the everyday running of our lives. The question for bodily becoming is not whether such potential is acceptable - although this is an important issue, it is rather more critically a case of how we manage the use of such technology in the twenty-first century and beyond. The question remains however of what an ethical approach to care will look like given the immense concentration of effort in creating technical artefacts of such sophistication and complexity. The ideal of perfection, precision and efficiency remains foremost in every imaginary field and the issue of care and concern for the effects such technology will have on humanity is considered technologically as secondary.

The nature and status of living matter

According to Braidotti et al the ideal of bodily perfection as 'the measure of all things' is represented in Leonardo da Vinci's universal model of Vitruvian Man that upholds a standardised view of what is human about humanity.[660] It sets standards not only for individuals but also for their cultures. Subjectivity as a civilisational ideal has been equated with masculinity, consciousness, universal rationality, and self-regulating ethical behaviour, whereas otherness or difference is regarded often as its negative counterpart. In so far as difference spells inferiority, it acquires essentialist connotations for those who get branded and reduced to the less than human status of disposable bodies. In short feminist ideals have been at best sold short or more likely suppressed or ignored. We are all humans, but

[657] The Sunday Times Magazine August 2017, The Tech Issue: Humans aren't working, www.thetimes.co.uk/magazine/the-sunday-times-magazine/technology accessed 27/08/2017.
[658] BBC News, Technology, www.bbc.co.uk/news/technology accessed on 29/01/2015.
[659] The Times 8th September 2017 article: Pay with a smile as Chinese take face recognition to fast food tills.
[660] Braidotti, R., (2013) p12, see also Foucault (1970), Irigaray (1985), Kristeva (1991), Ware (1992)

some of us are just more mortal than others. Braidotti suggests that such a restricted notion of what counts as human is one of the keys to understand how we get to a posthumanity.[661] When Foucault published his ground breaking critique of Humanism in *The Order of Things* the question of what, if anything, was the idea of 'the human' had set the anti-humanist agenda for an assortment of political groups.[662] Individualism he argued is not an intrinsic part of human nature but historically and culturally specific, and shown to be increasingly problematic.[663] Irigaray many years later argued that the philosophical and ethical stance of Humanism is neither an ideal nor an objective statistical average or middle ground, pointing out that the allegedly abstract ideal of Man as a classical symbol of humanity is exclusive.[664] It spells out a systematised standard of recognisability, of sameness by which all others can be assessed regulated and allotted to a designated social position. And Vron Ware comments that such a standard as categorically and qualitatively distinct form the sexualised, racialised, naturalised others, results in passing off entire categories of human beings as devalued and therefore disposable others; to be 'different from' means to be 'less than.'[665] Structural ignorance about those who, by being others, are positioned outside of major categorical divides in the attribution of humanity in many public institutions remains prevalent it seems.[666]

Change is necessary in order to engender inclusivity and reframe the otherwise limiting readings of humanity which those in positions of authority and power have traditionally fostered. Thus systems of scientific validity, ethical values and representations that support restrictive forms of power, in the name of inclusivity would benefit from being deconstructed and dislodged from a belief in the natural foundations of socially coded and enforced difference. Julia Kristeva in her book *Strangers to Ourselves* advocates the need to open up the 'others within' the social framework in such a way as to 're-locate diversity and multiple belongings to a central position as a structural component of subjectivity within diverse cultures.'[667] She believes that power formations not only function at the material level but are also expressed in systems of theoretical and cultural representation, political

[661] Braidotti, R., (2013) p15
[662] Foucault, M., (1970) *The Order of Things: Archaeology of Human Sciences*, Routledge, New York.
[663] Braidotti, R., (2013) p24
[664] Irigaray, L., (1985)
[665] Ware, V., (1992) *Beyond the Pale, White Women, Racism and History*, Verso, London.
[666] Pay equality for women in sport, in executive positions in large companies and so on, and in the media are amongst the most reported issues in general even as this thesis is in process in 2017. See www.telegraph.co.uk/business/2017/09/25/gender-pay-gap-widens-12000-female-managers/ accessed 26/09/2017.
[667] Kristeva, J., (1991) *Strangers to Ourselves*, Columbia University Press, New York. Ch.1.

and normative narratives and social modes of identification.[668] Thus it would seem that a more complex and relational subject is required, framed by embodiment, sexuality, affectivity, empathy and desire as core qualities and a profound understanding that power can be used as *both* a restrictive *and* productive force.

For posthuman concepts to be validated a departure in scientific thought from the categorical distinction between the given (nature) and the constructed (culture), which has hitherto enjoyed widespread consensus, is vital. Posthuman thought resists such a binary opposition having been superseded by the non-dualistic understanding of the interaction between nature and culture. This consequential blurring of boundaries, paradoxically, results from the effects of scientific and technical progress. As Braidotti argues the common denominator for the posthuman condition is an assumption about the vital self-organising and yet non-naturalistic structure of living matter itself. Matter, including human embodiment is intelligent, it is not dialectically opposed to culture, nor to technological mediation, but continuous with them. And so the nature-culture continuum is the shared starting point for reading and redefining matter through posthumanity.[669] It is a speculative approach to bodily perception that has profound and wide-ranging implications for the future of bioethics in research. Sharp believes that 'it is a concerted attempt to uncover what scientists themselves think they are doing as a means, in turn, to inspire them to reflect more broadly and deeply on the complexity of what is at stake as they toil away in the seclusion of their laboratories.'[670]

Matter and new materialisms

Keller and Mary-Jane Rubenstein suggest that the new materialisms 'currently coursing through cultural, feminist, political and queer theories seek to displace human privilege by attending to the agency of matter itself.'[671] New materialists argue that matter, far from being passive or inert acts, creates, destroys and transforms, and thus is more of a process than a thing.[672] Diana Coole and Samantha Frost write 'matter *becomes* rather than matter *is*.'[673] Calling on quantum ideas, general relativity, complexity theory and non-linear biology

[668] Kristeva, J., (1991) Chs.8 & 9
[669] Braidotti, R., (2013) pp2-3
[670] Sharp, L A., (2014) p19
[671] Keller, C., & Rubenstein, M-J., (2017) (eds.) *Entangled Worlds: Religion, Science and New Materialisms*, Fordham University Press, New York.
[672] Keller, C., & Rubenstein, M-J., (2017) pp2-3
[673] Coole, D., & Frost, S., (2010) p10

to posit matter as mattering, theorists rally against much of what is often denigrated as 'mere' materialism - rejecting the buying of endless unnecessary goods - to reveal 'the vitality of matter' itself.[674] Proclaiming 'the ontological equality of every discrete thing' theorists affirm the epistemological strength of quantum argument that actual entities are multiplicities, assemblages, hybrids, intra-actions, complexities and viscous porosities.[675] All terms which take their expression from quantum insight that each cell, organism and proton is irreducibly composed of an intra-active host of others. And this fundamental alterity holds for humans as for everything else. In this vein Gilles Deleuze and Felix Guattari state, 'Each multiplicity is symbiotic; its becoming ties together animals, plants, microorganisms, mad particles, a whole galaxy.'[676] And William Connolly proposes that the focus is on 'our entanglements with heterogeneous entities and processes in a world in which humanity matters immensely.'[677] Humanity matters for good and for ill from the perspective of the vast variety of nonhuman beings composing the life of the planet. As Donna Haraway reminds us, 'To be one is always to *become with* many.'[678] In other words, we are entangled beings, and entanglement from the perspective of quantum concepts shows that all tangibility entails an infinite alterity, so that touching the other is touching all others, including the self. According to Karen Barad, although we bring vast histories and habits, we bring them for the sake of an entangled becoming.[679]

The relatively new attention to matter touches on deep levels of meaning. Beginning 'first agents' which are the simplest biochemical systems in which we can distinguish 'teleology', Philip Clayton and Elizabeth Singleton discern each living thing as a network of intentions, environments, adaptations, communications, toxins, nutrients and porosities.[680] In agreement with Barad they reveal living matter's primordial entanglement with meaning. This systemic bio-semiotics entails therefore an 'ethic of embodied responsibility.'[681] After all, to recognise living beings as *valuable*, not simply in themselves but rather as participants in the entire system of life; bonded by networks of bodies and objects, and collectively

[674] Coole, D., & Frost, S., (2010) p10
[675] Keller, C., & Rubenstein, M-J., (2017) p1
[676] Deleuze, G., & Guattari, F., (1987) *A Thousand Plateaus*, Massumi, B., (trans) University of Minnesota Press, Minneapolis, p250.
[677] Connolly, W., (2013) *The Fragility of Things: Self-Organizing Processes, Neoliberal Fantasies and Democratic Activism*, Duke University Press, Durham, North Carolina, p49.
[678] Haraway, D., (2007) *When Species Meet*, University of Minnesota Press, Minneapolis, pp3-4.
[679] Barad, K., (2017) What Flashes Up in Keller, C., & Rubenstein, M-J., (eds.) *Entangled Worlds: Religion, Science and New Materialisms*, Fordham University Press, New York, p71.
[680] Clayton, P., & Singleton, E., (2017) Agents Matter and Matter Agents, in Keller, C and Rubenstein, M-J., (eds.) *Entangled Worlds: Religion, Science and New Materialisms*, Fordham University Press, New York, pp 138-139.
[681] Clayton, P., & Singleton, E., (2017) pp138-139

composing the interdependent biosphere through and in which anything that lives, lives, Barad suggests:

> [Is] an ethics of entanglement [that] entails possibilities and obligations for reworking the material [configurations of] the past and the future…it is not the case that *the* past - a past that is [allegedly fixed and] given can be changed - contrary to what some physicists have said, or that the effects of past actions can [thereby] be fully mended, but rather the 'past' is always already open to change. There can never be complete redemption [in the sense of a full restoration of the way it was], but spacetimematter can be productively reconfigured, as im/possibilities are reworked.[682]

In taking quantum field theory Barad explains that there is an important sense in which the eternal/infinite does in fact operate within and through matter in its very constitution and as a constitutive alterity. The infinite touch of nothingness is threaded through all being/becoming, a 'tangible indeterminacy that goes to the heart of the matter.' Matter is not only iteratively reconstituted through its various interactions, 'it is also infinitely and infinitesimally shot through with alterity.'[683]

Equally Abhinavagupta's theories of the entanglement of consciousness and matter lead to a reconsideration of the nature of the body.[684] Not simply inert matter, the body's parameters shift in this formulation to afford the status of 'body' with the mutuality of matter and consciousness. That is his conception of the body incorporates both materiality and reasoning entwined together, understood as the subtle body.[685] The subtle body is fundamentally made of matter, yet it links with consciousness that extends its capacities beyond the physical body.[686] Invisible to sight even though it is connected to the five senses and is itself sensible, it is the subtle body that transmigrates from life to life for those various Indian philosophies that affirm re-birth. In contrast the Western concept of soul - as a permanent and unique individual essence - is problematic for certain Indian philosophies that support the notion of the soul that outlasts the physical body, a soul which is subject to its own transformations and becomings. Lorilai Biernacki argues for this unfamiliar map of the body as helpful since it allows us to gather unexpected and useful new formulations of the relation between body and mind. Maintaining that the subtle body particularly

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[682] Barad, K., (2017) p49

[683] Barad, K., (2017) p71

[684] Abhinavagupta lived from about 950-1025 CE and was the great grand-disciple of Somananda of the Kashmiri Saivism school called 'Pratyabhijna' or 'Recognition' – his writing might be read as part of a larger trend within Tantric philosophy to bring the body back, (in contrast to Vedanta the dualist philosophy which privileged mind over matter), recognising the importance of the body and matter.

[685] Flood, G., (2006) *The Tantric Body: The Secret Tradition of Hindu Religion*, I. B. Tauris & Co. Ltd., London, pp56-57.

[686] See Ch.2 p44 of this study.

'demonstrates a permeability in its ontological characterization, entangling both materiality/body and consciousness as productions of ritual performance.'[687]

A significant posthuman development clearly comes from studies of science and technology. The pride in technological achievements and in the wealth that comes from them does not prevent us from seeing the great contradictions and the forms of social and moral inequality provoked by our advanced technologies. What is striking about science and technology studies is the high degree of neutrality expressed about the posthuman predicament. Researchers Nicholas Rose, Sarah Franklin et al, however tend to dismiss a revised vision of the subject, they make it clear that the focus of their research is analytic, aiming to achieve a better, more thorough understanding of how new technologies function.[688] For them, subjectivity is out of the picture and with it goes a sustained political analysis of the posthuman condition. However, analytical attempts to moralise technology and sideline experiments with new forms of subjectivity neglect the current state of autonomy reached by machines. A focus on subjectivity *is* necessary because this notion enables us to string together issues that are currently scattered across a number of knowledge domains. Issues such as norms and values, forms of community bonding and social belonging as well as questions of political governance assume and require a notion of the subject.[689]

Biotechnological developments as ethically problematic

Coole and Frost maintain there is something unprecedented about our contemporary situation in which the prefix 'bio' proliferates.[690] Molecular biology and its equivalents are achieving the sort of privileged status previously reserved for theoretical physics, fuelled by a revolution in biomedicine and biotechnology. This in turn is propelling an unprecedented range of issues concerning the nature and status of living matter and defining what we see as a major development in the concept of materialism. In life sciences as well as in physics material phenomena are increasingly being conceptualised not as discrete entities or closed systems but rather as open, complex systems with porous boundaries. Such theories challenge earlier distinctions between physical and biological systems drawing attention to

[687] Biernacki, L., (2017) Material Subjects, Immaterial Bodies in Keller, C and Rubenstein, M-J., (eds.) *Entangled Worlds: Religion, Science and New Materialisms*, Fordham University Press, New York, P186.
[688] Rose, N., (2007) *The Politics of Life Itself: Biomedicine, Power and Subjectivity in the Twenty-First Century*, Princeton University Press, Princeton, and Franklin, S, Lury, C and Stacey, J., (2000) *Global Nature, Global Culture*, Sage, London.
[689] Braidotti, R., (2013) p43
[690] Coole, D., & Frost, S., (2010), p15

their interaction and transforming the way scientists think of biological matter and its interrelation with social phenomena.

Biotechnological developments that purport to enhance, extend or give us control over the hidden depths and minutiae of life have been considered negatively as merely contributing to a modern will to dominate nature. Their negative aspects and their inability to control the forces they unleash are also apparent, opening up a minefield of ambiguous ethical and political possibilities - bio-disasters such as Chernobyl and biological warfare involved in bio-terrorism being significant examples. As both promises and threats such developments call us to confront pressing bioethical and bio-political questions about the nature of responsibility, the relationship of humans to the world, the very definition of the human in relation to the non-human and the way shifting definitions of nature and life affect subjective experiences of selfhood. For while biotechnologies bring new tools and procedures for classifying, measuring, monitoring and modifying biological stuff within our daily routines, according to Rose so individuals' experiences of themselves as subjects and agents of their own lives are also transformed.[691]

Questions regarding the definition, the ethical value and the moral and political culpability of the human, the non-human and the virtual human become especially problematic since they prompt reflection upon who or what should be taken as subjects and objects of ethical, legal or political action: they also suggest a need for new ways of reflecting on risk and accountability as humans 'tinker' more readily in natural processes and thus become more materially, if not yet ethically responsible for the outcomes.[692] The blurring of clear boundaries or distinctions between bodies, objects and contexts is evident in the myriad biotechnological and digital technological developments that are changing the landscape of the living. Mind-boggling medical and digital prostheses now enable, enhance and enrich our physical and social lives in many ways. As discussed at the beginning of this chapter, medical and digital technologies have become part of our lives and of who we are. It is not merely the case that more people are becoming something akin to Haraway's cyborg - a fusion of human and technology.[693] More radically Katherine Hayles argues that we have been jolted out of the realm of the human into the realm of the posthuman and such changes have significant implications for our understanding of the human as a distinctive

[691] Rose, N., (2001) The Politics of Life Itself in *Theory, Culture and Society*: **18:6:1-30**
[692] Sharpe, L A., (2014) pp95-100
[693] Haraway, D., (1991) A Cyborg Manifesto: Science Technology, and Socialist-Feminism in the Late Twentieth Century in *Simians, Cyborgs and Women: The Reinvention of Nature*, Routledge, New York, pp149-181.

biological or moral entity.[694] It is becoming evident therefore that changes in living matter are rendering obsolete many of the conventional ethical categories used to evaluate them. As scientists succeed in bridging species, artificially creating and extending human life – including transplantation procedures, Coole and Frost maintain that the concepts and boundaries that are the ground for much ethical and political thinking are muddled. Synthetic life forms for example challenge the very conception of ourselves as persons since distinctions between intelligent and unintelligent life have prompted crucial efforts to distinguish humans from other animals and to justify humans' instrumental commandeering of material resources.[695] This raises questions of the kind of ethical value that should be attributed to synthetic life forms and according to what criteria.

As evidenced in debates about foetal rights, abortion, stem cell research, the use of animal organs to transplant into human bodies, medical, scientific, or religious accounts of the boundary between life and death are currently becoming further entangled with issues surrounding autonomy and personal decision-making because increasingly the state must legislate on matters that were formerly left to God or nature. Technological questions about biological life processes enter the political milieu because the state must frequently make decisions about the worthiness of different lives. Artificially suspending death through ventilation in order to preserve organs in a better state for transplantation is one such example, since it has obliged legislators in certain countries to alleviate organ shortage and thereby redefine death by shifting the final border of life.[696] According to Giorgio Agamben in the face of this 'bare life' that is sustained and controlled by human technologies, nature is no longer a reliable guide to the difference between life and death. Instead the distinction becomes a scientific, medical and 'ethicopolitical' question.[697]

Technological control over life and death

Significantly the posthuman digital universe gives rise to its own inhuman variables. Manifested by the proliferation of viruses both computer and organic, illness is clearly not only a prerogative of organic entities, but includes a widespread practice of mutual contamination between organic matter and electronic circuitry. Thus a rather complex

[694] Hayles, K N., (1999) *How We Became Posthuman: Virtual Bodies in Cybernetics, Literature and Informatics*, University of Chicago Press, Chicago.
[695] Coole, D., and Frost, S., (2010) p22
[696] Elective artificial ventilation is not legalised and has been under debate and discussion since 1995 in the UK: Coggan, J., Elective ventilation for organ donation: law policy and public ethics in *Journal of Medical Ethics* **2013:39:3:130** and Gillett G., Honouring the donor in death and life in *Journal of Medical Ethics* **2013:39:3:149**
[697] Agamben, G., (1998) *Homo Sacer: Sovereign Power and Bare Life*, Stanford University Press, Stanford, p119.

symbiotic relationship has emerged in our cyber universe - a sort of mutual dependence between flesh and the machine. This brings forward some significant paradoxes namely that the corporeal site of subjectivity is simultaneously denied in practices of human enhancement and in fantasies of escape via techno-transcendence and all the while increasing our own vulnerability. Anne Balsamo argues that digital technology promotes dreams of immortality and control over life and death:

> And yet, such beliefs about the technological future 'life' of the body are complemented by palpable fear of death and annihilation from uncontrollable and spectacular body threats: antibiotic resistant viruses, random contamination, flesh-eating bacteria.[698]

Spiritual death is also part of repositioning humanity. The currency granted to both legal and illegal drugs in contemporary culture blurs the boundaries between self-destruction and fashionable behaviour and forces a reconsideration of what is the value of life itself. Perhaps we need to re-think death altogether, the ultimate subtraction, as another phase in a generative process, and so we need to discuss more rigorously ways of dying as suggested.[699] Views on death depend on assumptions about life. Death is the unrepresentable, the unthinkable. Yet paradoxically death is a creative synthesis of the flow of energies and perpetual becoming. Deleuze suggests that to make sense of death we need an unconventional approach that rests on the preliminary and fundamental distinction between personal and impersonal death. The former is linked to the suppression of the individualised ego. The latter is beyond ego: a death that is always ahead of me and marks the extreme threshold of my powers to become. Because humans are mortal, death or the transience of life, is written at our core: 'it is the event that structures our time-lines and frames our time zones, not as a limit but as a porous threshold.'[700] Death is the event that has always already taken place at the level of consciousness. As an individual occurrence it will come in the form of physical extinction of the body but as an event in the sense of the awareness of finality, of the interrupted flow of my being there, death has already taken place. We are all synchronised with death - death is the same thing as the time of our living, in so far as we all live on borrowed time. Life is passing and so we do not own it; we just inhabit it.

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[698] Balsamo, A., (1996) *Technologies of the Gendered Body: Reading Cyborg Wom*en, Duke University Press, Durham, North Carolina, pp1-2.
[699] See Chs.2 & 7 sections on death in this study.
[700] Deleuze, G., (1995) *Philosophie*: **47:3-7**

Virtual life

The relationship between body and self is thrown into question by the spread of virtual forms of embodiment and electronically mediated communities. Human ontology is digitalised, yet if identity is reconstituted as pure data or information as text then the corporeal nature of embodiment becomes more problematic. Elaine Graham believes that the absorption of bodily presence into a purely digital embodiment may well suggest the effacement of the body, such that participation in cyberspace is necessarily post-corporeal.[701] Thus if persons have no 'fleshy' substance in cyberspace, this raises the question of whether it is still appropriate or meaningful to link the traditional ideas of identity, freedom, agency or community with notions of corporeality or physical space. The issue of the dissolution of the material into the virtual has proven contentious, especially for those who regard the immediacy of the body as constituting an ethical imperative.[702] Dan Thu Nguyen and Jon Alexander believe that:

> Our virtual life in cyberspace paralyses our bodies. Cyberspacetime promises us liberation from the constraints of space, time and materiality. However, without the experiences of our bodies, our thoughts, our ideas, our ethics and politics must all suffer. We know ourselves and our world mainly because we live and move in the world through our bodies.[703]

Such comments however, depend on an appeal to an essentialist body as any ground of ethics. But any appeal to the body as an uncomplicated locus of identity renders problematic advanced medical and digital technologies that displace the givenness of corporeality.

Arguably by contrast virtual reality still depends in a residual sense upon bodily proprioception and conventions of space movement and perspective transferred from embodied experience.[704] Far from abandoning the body, forms of virtual interaction retain many of the conventions of face-to-face community. In thinking of emails for instance, the emoticon has taken the place of gesture to enhance the comprehension of dialogue. Thus it may be more appropriate to think of cyberspace as a transitional state where the subject is both *materially* and *digitally* embodied. 'The literal body may not be communicated within

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[701] Graham, E L., (2002) *Representations of the post/human: Monsters, Aliens and Others in Popular Culture,* Manchester University Press, Manchester, p187.
[702] Graham, E L., (2002) p188
[703] Nguyen, D T., & Alexander, J., (1996) The Coming of Cyberspacetime and the End of Polity in Shields, R (ed.) *Cultures of Internet: Virtual Spaces, Real Histories, Living Bodies*, Sage, London, p117.
[704] A sense of the body's position - particularly the limbs - in space.

the net, but it is possible to conceive of a multiplicity of ways of being a virtual body that reflect a subjectivity which inhabits many levels of corporeal presence.'[705] Virtual interactions may simply accentuate the extent to which subjectivity has never been a constant. Thus identity in a cyberworld is fluid and negotiable. Just as various cybernetic and genetic technologies are dissolving the notion that bodies end at the skin, suggestive of physiologically and psychologically porous subjects, negotiations with the multiple domains of virtuality reveal decentred subjects for whom, as Graham states 'unitary identity could be seen as a cumbersome and irrelevant fiction.'[706]

The potential of biotechnological developments

Recall the argument in Chapter 2 that human subjectivity cannot be equated with a single privileged aspect however, such as mental functioning. Rather the mind and the self are themselves intertwined physically and proprioceptively. The subject is always an organic, technological body in relation, both creative agent and created subject within its changing environment. Therefore technologies need to be seen as co-evolving and intermingled agents in the construction of the posthuman. This view is a shift from technophobia - and a view of technology for that matter as monolithic, undifferentiated, beyond human agency - towards the reclaiming of technologies as heterogeneous and primary in their capacities to mediate the human. Equally there is no essential body. The end of the human need not necessarily entail a choice between 'impersonal, deterministic, technologised, posthumanism and organic, unmediated, autonomous natural subjectivity,' as Graham proposes.[707] Rather it may involve modes of posthumanity in which tools and environments are vehicles of, rather than impediments to the formation of embodied identity.

In *A Cyborg Manifesto* Haraway terms the 'blasphemy' of cyborgs as transgressive, hybrid creatures who destabilise the very categories on which Western scientific logic depends. Her vision encapsulates a digital, biotechnological age, and how advanced genetic, digital, biochemical, cybernetic and mechanical techniques have made possible countless new configurations of the organic body through prosthesis, permanent or temporary modification and therapies. Cyborgs inhabit a world simultaneously biological and technological. As living fusions of the human and non-human animal, the human, the mechanical, the organic and

[705] Graham, E L., (2002) p190
[706] Graham, E L., (2002) p191
[707] Graham, E L., (2002) p198

the fabricated, they render transparent the 'leakiness' of modernity's boundaries between species and categories.[708] Haraway's theorising is thus a patterned vision of how to move and what to fear in the 'topography of an impossible but all too real present' in order to find 'an absent, but perhaps possible, other present.'[709]

We might say that the cyborg is a handy metaphor for posthuman experiences that defy models of technology as a deterministic, monolithic force or as a 'quick fix' whose social and political implications are somebody else's concern. Global techno-science reduces everything to an artefact, a thing made not born, while representing nature as primal, innocent and independent of human agency. But what we call 'nature' is already heavily managed by techno-scientific interests, such that any notion of 'nature outside of culture is not so much elsewhere as nowhere.'[710] In other words it does not exist. It would therefore be inappropriate to build an ethic on an imagined organic unity with such a construction, but *the challenge is to express new forms of relationality that embody affinity and difference but not dominion.* Ethically and experientially, the cyborg is a heuristic that suggests the rejection of solutions of either denial or mastery in favour of a posthuman ethic grounded in participation with non-human nature, animals and machines.

The sense that humans and machines are increasingly assimilated, that human nature cannot be realised apart from its tools and artefacts is, according to Graham, a more authentic understanding of posthuman ontology in a digital and biotechnological age. It is also a profoundly materialist understanding because it refuses to believe either that 'humanity can retreat to some pure unadulterated human nature independent of the world it makes; or that technologies can be exploited to transcend bodily finitude and limitation. Humanity is actually constituted in reflexive interaction - even co-evolution- with tools, environment and artefacts.'[711]

As Richard Doyle argues:

> The very success of the informatics paradigm, in fields as diverse as molecular biology and ecology, has paradoxically dislocated the very object of biological research…This postvital biology is, by and large, interested less in the characteristics and functions of living organisms than in sequences of molecules and their effects.

[708] Haraway, D., (1991) pp152-153
[709] Haraway D., (1992) The Promises of Monsters in *Cultural Studies*, Grossberg, L., Nelson, C., & Treichler (eds.), Routledge, New York, pp295.
[710] Haraway D., (1992) p295
[711] Graham, E L., (2002) p229

> These sequences are themselves articulable through databases and networks; they therefore garner their effects through relentless repetitions and refrains, connections and blockages rather than through the autonomous interiority of an organism.[712]

Posthuman concepts and humanity

Life is post-vital in the same way that humans may be considered posthuman. This is not a shift in life or humanity *per se*. It is a shift in our way of *thinking* life and humanity. Life has been blocked by a narrative of subjectivity that has hitherto held to a model of linear time that presupposes categories of meaning based on established representations. According to Manning 'the becoming-silicon of flesh and the becoming-flesh of silicon point toward not a radical change but an enactment of the manner in which the body has always been multiple.'[713] The concept of posthumanity focuses on the relation between the body and embodiment, leading us toward 'a body without organs' that engages with the world not by means of pre-established limitations, but through an emergent network that overlaps prosthetic and organic devices.[714] For Hayles 'the posthuman view thinks of the body as the original prosthesis we all learn to manipulate, so that extending or replacing the body with other prostheses becomes a continuation of a process that began before we were born.'[715] Bodies exceed our knowledge of them. Relationally we begin not to think in terms of the order of causes and effects, bodily processes and actions. We compose with bodies. Bodies emerge not only as what they are but what they expressively can become.

Post humanity gives us a vocabulary to think through prosthetics in relation to the senses. In a humanist vocabulary bodies are more likely to be thought of as unified and unique. The posthuman on the other hand takes the prosthesis as a condition of the organism as its supplement. Since the human does not become prosthetic but rather is already prosthetic, Hayles writes:

> …the posthuman view configures human being so that it can be seamlessly articulated with intelligent machines. In the posthuman there are no essential differences or demarcations between bodily existence, and computer simulation, cybernetic mechanism and biological organism, robot teleology and human goals…the posthuman subject is an amalgam, a collection of heterogeneous

[712] Doyle, R., (2003) *Wetwares: Experiments in Postvital Living*, University of Minnesota Press, Minneapolis, p21.
[713] Manning, E., (2007) p120
[714] Manning, E., (2007) p120
[715] Hayles, K N., (1999) p3

> components, a material informational entity whose boundaries undergo continuous construction and reconstruction.[716]

The question is of how to think of the body as always already prosthetic. I am an organism. I breathe, my heart beats, my pancreas controls the sugar levels in my blood, my skin regenerates, my brain disseminates waves of information and so on. But I am also much more than an organism. 'I breathe a smell that tastes like the morning. The morning reminds me of the texture of the wood of the breakfast table, rough to the touch in places.'[717] To 'be' a body is to become. To sense is to live beyond the mere organism. Sensing is not essential to the organic body. But without my senses I am not aware of the flesh as 'body.' It is in this manner that senses are prosthetic; they are in excess of the organic, yet they make the organic palpable. To think the senses as prosthetic invites us to explore the surprising pathways toward which our senses lead us. These movements are never direct. They are interlaced, entangled, have a sense of location and are nonlinear. In fact we cannot know in advance what the body can do. Biology points toward the complexities of bodies in relation. Biologically even the body is always less that what it can and will become and more than what we can imagine or foresee. A body that is open to the processes of individuation is a posthuman body, one that remains ever in the process of becoming. To think of the posthuman body is to open ourselves to thinking about the body that exceeds the norm. 'It is to begin to engage creatively with what a body can do, with what a body becomes.'[718]

Classical emphasis on the unity of all matter central to Baruch Spinoza's philosophy has been reinforced by an updated scientific understanding of the smart structure of living matter.[719] Smart concepts are supported by new advances in contemporary biosciences, neural and cognitive approaches and equally by informatics.[720] Posthuman subjects are technologically mediated to an unprecedented degree. A direct connection between Spinoza's monism, the unity of all living matter and post-anthropocentrism could form a general frame of reference

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[716] Hayles, K N., (1999) p3
[717] Manning, E., (2007) p157
[718] Manning, E., (2007) p 151 - recalling Spinoza's concepts of the body and becoming – see reference 695 below.
[719] A monistic universe refers to Spinoza's central concept that matter, the world and humans are not dualistic entities structured according to principles of internal or external opposition. The implied target is Descarte's mind/body distinction, but for Spinoza the concept goes even further: matter is one, driven by the desire for self-expression and ontologically free. Spinoza's legacy consists in a very active concept of monism that defines matter as vital and self-organising, rejecting all forms of transcendentalism. Monism results in relocating difference outside the dialectical scheme, as a complex process of differing which is framed by both internal and external forces and is based on the centrality of the relation to multiple others.
[720] Smart here refers to techniques such as gene splicing and editing for instance to eradicate certain forms of disease, and moreover to advanced (intelligent) technology in informatics underlying the manipulation of robots for example.

for contemporary subjectivity save that division exists in mainstream public debates; the posthuman as a concept either overwhelms or engenders anxiety about the excess of technological intervention and the threat of job loss or climate change, or inspires elation about the potential for human enhancement. Thus the post-anthropocentric turn linked to the compounded impact of globalisation and technologically-driven forms of mediation strikes humanity at its heart which consequently shifts too radically the parameters that used to define humanity. The key question is what kind of understanding of contemporary subjectivity and subject-formation are enabled by a post-anthropocentric approach?[721] How we relate to this change of perspective depends to a large extent on our relationship with technology. One of the most pointed paradoxes of our era is precisely the tension between the urgency of finding new and alternative modes of political and ethical agency for our technologically mediated world and the inertia of established habits. Donna Haraway once wittily remarked: 'the machines are so alive, whereas the humans are so inert.'[722]

Scientific advances in molecular biology have taught us that matter is self-organised - *autopoietic*, and monistic philosophy adds that it is also structurally relational and hence connected to a variety of environments. These insights combine in defining intelligent vitality or self-organising capacity as a force that is not confined to human beingness but is present in all living matter. Matter is conceived as intelligent because it is driven by such informational codes that interact in multiple ways with social, psychological and ecological environments. So what happens to subjectivity in this complex field of forces and flows of data? Braidotti infers that it becomes an expanded and relational self, engendered by the cumulative effect of all these factors.[723] The relational capacity of the posthuman subject is not confined within our species but includes all non-anthropomorphic elements. Living matter - including the flesh - is intelligent and self-organising, but is so precisely because it is continuous with the rest of organic life.

Thus the posthuman dimension of post-anthropocentrism can consequently be seen as deconstructive. What it deconstructs is not only the supremacy of the human being, but it also rends asunder any lingering notion of human nature as categorically distinct from the life of animals and non-humans. What comes to the fore instead is a nature-culture continuum in the very embodied structure of the extended self and a massive hybridisation of the species. This alternative becoming entails the displacement of anthropocentrism and

[721] Braidotti, R., (2013) pp56-58
[722] Haraway, D., (1991) pp149-181
[723] Braidotti, R., (2013) p59

the recognition of trans-species solidarity on the basis of our being environmentally based, that is to say embodied, embedded and in symbiosis with other species. It breaks open the division between humans and technology, introducing bio-technologically mediated relations as ground for the constitution of the subject. Thus we need to apply this 'matter realism' as the foundation for a system of ethical values where life stands central.[724] Post-anthropocentrism displaces the notion of species hierarchy and of a single, common standard for 'man' as the measure of all things.[725] As discussed earlier in this chapter, such a standard has been upheld by aesthetic and moral ideals - that is to say the status of man as the dominant species whose sense of entitlement includes access to the body of all others. The posthuman predicament is such as to force a displacement of the lines of demarcation between structural differences or ontological categories, for instance between the organic and the inorganic, male or female, the born and the manufactured, flesh and metal, electronic circuits and organic nervous systems.[726]

Posthumanity and an ethical approach to care

According to a report in the Economist - Morals and the Machine - humans will increasingly operate not 'in the loop' but 'on the loop' monitoring working with robots rather than fully controlling them.[727] Only ethical and legal issues remain to be solved to grant responsibility to autonomous machines' decision-making, while the supposed cognitive capacities are already in place. Should robots be engaged in disaster relief for instance, or tell people the truth about the condition of their health thus possibly causing panic and pain? Such questions involve the field of 'machine ethics' that aims to give machines the ability to make choices appropriately concerning the telling of right from wrong or even sick from healthy. The idea of morals and the machine raises some pertinent issues about the degree of autonomy reached by robots and calls for society to develop new rules to manage them.[728]

[724] Braidotti, R., (2013) pp65-68
[725] See Irigaray (1985) and Deleuze & Guattari (1987)
[726] Braidotti, R., (2013) pp90-92
[727] The Economist 2nd June 2012 Morals and the Machine at www.economist.com/node/21556234 accessed 28/09/2015.
[728] The Daily Telegraph: Lifestyle: Men, 6th June 2016 article: Is a robot about to take your job?

This is significant and in contrast to the modernist idea of the robot as subservient to the human, exemplified by Asimov's 'three laws of robotics' formulated in 1942.[729] A set of three laws which interestingly are reflected in Principlist ethics developed some decades later, and substantiating an inert rather than creative or fluid idea of morality at the everyday level.

We are confronted with a new situation that could make human intervention peripheral if not completely irrelevant. As robots appear to become more autonomous, the notion of computer-controlled machines facing ethical decisions is moving out of the realm of science fiction and into the real world. The burning question remains whether machines are in fact capable of such autonomy when faced with the nature of soft or subtle problems. Who or what is to decide? Who or what will be the judge? Problematic as this may be, the issue might rest on the management of advanced technology in terms of a responsibility and caring for the outcome of the fruits of such progress; understanding and acting responsibly on the kinds of transformation that the techno-body will potentially undergo has profound implications for creating a progressive vision of wider humanity - of the merging of science and nature-cultures.

What does caring mean when we go about thinking and living interdependently with beings other than human, in more than human worlds. Is it possible to think of care as an obligation that cuts across the nature-culture divide without simply re-instating the dualities and moralism of human-centred ethics? How can engaging with care aid in thinking moral obligations in human-decentred worlds? Care offers possibilities for considering commitment and obligation as non-normative forms of ethical engagement that could be more attuned to the de-centring of human agency and privilege in contemporary understanding of techno-science and nature-cultures. De la Bellacasa argues that the problem will be of not falling back into classical humanist categories of thought, but will require 'much speculative effort.'[730] According to Sharp, 'Involved bioengineers often speak of the "messiness" of the flesh as what drives them to perfect their mechanical devices.'[731]

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[729] The three laws are: 1) A robot may not injure a human being or through inaction, allow a human being to come to harm. 2) A robot must obey the orders given to it by human beings, except where such orders would conflict with the First Law. 3) A robot must protect its own existence as long as such protection does not conflict with the First or Second Laws. These rules were established by Isaac Asimov in a short story in 1942 and then re-printed in the best seller *I*, *Robot*, in 1950. They became foundational notions in cyber-studies. Later Asimov added a fourth law which precedes all others: 0) A robot may not harm humanity, or by inaction, allow humanity to come to harm.

[730] De la Bellacasa, M P., (2017) p13

[731] Sharp, L A., (2014) p112

And somehow mechanical implants such as heart pumps are 'imagined as ethics free.'[732] The reclaiming of care in approaches to more than human worlds established by techno-science defies traditional ethical boundaries that have hitherto marked critical thinking. Following the image of care into 'unexpected country' of blurred boundaries - moral as much as material - requires opening up its possible meanings.[733] Relocating caring in more than living ecologies will involve discussions of techno-science as knowledge and material production interrelated with socio-political processes including those of commodification. As Barad theorises, it is through entangled agencies and practices of matter and meaning that techno-scientific worlds come to matter.[734] It involves thinking about how things could be different. It most certainly involves multi-vocality - a focus on protagonists and critics in advancing technological artefacts. It involves how to care about the way artefacts are constructed, presented, studied and used, especially when care seems to be expendable.

Conclusions

We might conclude that hybrids are the dominant social and cultural developments that are active throughout the social fabric of society. Technological mediation is central to a new vision of posthuman subjectivity and provides the ground for new ethical claims. Machinic vitality is not so much about having inbuilt purpose or finality, but rather about becoming and transformation.

> The emphasis on immanence allows us to respect the mutual dependence between bodies and technological others while avoiding the contempt for the flesh and the trans-humanist fantasy of escape from the finite materiality of the enfleshed self.[735]

It involves a radical distancing from notions like moral rationality, unitary identity, transcendent consciousness or innate and universal moral values. The focus is entirely on the *normatively neutral relational structures* of both subject formation and of *possible ethical relations.*

Posthuman theory cuts to the core of classical visions of subjectivity. It is about coming to terms with unprecedented changes and transformations of the basic unit of reference for what counts as human. The problem remains however that the collapse of the nature-

[732] Sharp, L A., (2014) p143
[733] Haraway, D., (2007) *When Species Meet*
[734] Barad, K., (2007) *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning*, Duke University Press, Durham.
[735] Braidotti, R., (2013) p91

culture divide entails the need to devise a new vocabulary, with new configurations to refer to the elements of our posthuman embodied and embedded subjectivity. We also need to reconceptualise the relation to the technological artefact as something as intimate and as close as nature used to be. Unlike Hayles, Braidotti in agreement with Manning, believes that the technological apparatus is our new milieu and this intimacy is far more complex and generative than the prosthetic, mechanical extension that modernity has made of it.[736]

Our public morality is simply not up to the challenge of the scale and complexity of damages created by our technological advances. This gives rise to a double ethical urgency: firstly how to turn anxiety and the tendency to mourn the loss of the natural order into effective social and political action, and secondly how to ground such an action in the responsibility for future generations.

The human organism is an in-between that is plugged into and connected to a variety of possible sources and forces. 'The minimalist definition of a body-machine is an embodied affective and intelligent entity that captures processes and transforms energies and forces.'[737] Being embodied in a high tech manner entails full immersion in fields of constant flows and transformations. Thus we need to investigate and experiment with new practices that allow for a multiplicity of possible instances of the different lines of becoming. Lines that need accounting for in any ethical representation. The specific temporality of the posthuman subject needs to be re-thought beyond the metaphysics of mortality. The subject is an evolutionary engine endowed with his or her own embodied temporality both in the sense of genetic code and individualised memories. Braidotti advises:

> If the embodied subject of bio-power is a complex molecular organism, a bio-chemical factory of steady and jumping genes, an evolutionary entity endowed with its own navigational tools and an in-built temporality, then we need a form of ethical values and political agency that reflects this high degree of temporal complexity.[738]

Such an ethical approach cannot be disassociated from considerations of power. The egalitarianism that is potentially conveyed by the current technological transformations has dire consequences for human views of the subject. Far from being merely a crisis of values we are confronted by a formidable array of new opportunities. They converge through different perceptions on a re-composition of our shared understanding of the human as species. But the image of post-anthropocentric thought goes much further in the

[736] See Hayles' quote on p203 of this study.
[737] Braidotti, R., (2013) p140
[738] Braidotti, R., (2013) p140

deconstruction of the subject, because it stresses radical relationality, that is to say non-unitary identities and multiple allegiances. As this shift occurs it opens up new approaches. It is entirely feasible that technologically mediated post-anthropocentrism can engage the resources of biogenetics, epigenetics, telecommunication, new media and information technologies, in the task of renewing perspectives on humanity. 'Posthuman subjectivity reshapes the identity of human practices by stressing difference and multi-faceted relationality, instead of autonomy and self-referential disciplinary purity.'[739] The posthuman predicament enforces the necessity to think again and to think harder about the status of the human, the importance of recasting subjectivity and the need *to invent forms of ethical relations, norms and values worthy of the complexity of our times.*

[739] Braidotti, R., (2013) p186

Concluding Remarks

In the Introduction and Background to this study I stated that my aim was to find an alternative bioethical approach to the dominant Principlist model developed by Beauchamp and Childress taught in numerous medical schools globally. It is a model that has been heavily criticised for its lack of suitability in providing guidance for difficult medical decision-making. In order to frame a different approach I concentrated on four interrelated aims: firstly to focus attention away from Western approaches to medical interpretations of the body, to an alternative model which sees the body as complex – wholistic, meaningful, relational and constantly in a state of flux; secondly focused examination of the Principlist bioethical framework, which underpins the Western medical approach to healing and care, as fit for purpose; thirdly to propose a different approach to bioethics that will support not only ethical decision-making but place the unique needs of the patient at the centre of caring in medical praxis; and finally a return to understanding the body from an alternative perspective as a speculative examination of the recasting of subjectivity and caring. I reasoned that as the blurring of boundaries between bodily existence and ever more sophisticated technology continues to evolve apace it will become vitally important to frame different bioethical questions and resolutions.

I chose to read the issues in bioethics through the processes of organ donation and transplantation primarily because the topic is present-day, but more importantly because medical decision-making in this area sits at the extreme limit of the ethical spectrum. Donation and transplantation processes push the limit in respect of how the body is to be

seen, treated and valued, a specialist area of medicine that I perceived would provide a robust example in arguing for an alternative to current bioethical thinking. Given my views on the body, the key question 'What do we mean by the body?' became a critical starting point, a suitable end point and the pivot for the whole of the study.

I perceived the problem in the Principlist model to be too simplistic in its consideration of the wider understanding of the body, basing this supposition on many years of experience as a kinesiologist, embracing narrative as a useful tool for accessing the healing process. Adherence to the Western medical model that favours an approach to the body as merely organic is too narrow and is rendered problematic. Such a model exacerbates an already dualist, reductionist perspective of humanity resulting in restrictive bioethical models developed by a number of bioethicists. The Principlist framework encompassing the four bioethical criteria of autonomy, beneficence, non-maleficence and justice created by Beauchamp and Childress rather values rational and intellectual control over medical matters leading to norms that are prescribed and limiting. The key issue lies in the notion that different kinds of body and different ways of enacting what it means to be human shifts the emphasis to the infinite variability of what bodies can become. In addressing such fluid bodily becoming, it transpired that an incarnational approach offered insights that thoroughly underpin the concept of the body that I wished to put forward in challenging the Principlist framework. Arguing for an incarnational approach that reveals our multi-faceted, embodied nature, the notion that a failure to love passionately all that we see, touch, taste, smell and hear, has significant implications for meeting the needs of humanity's deeply embedded suffering in general but for those who are sick in particular. Given a fluid interpretation of the body and the inherent attributes we all share that contribute to healing, restrictive bioethical criteria I believe underplay the kinds of care necessary to promote healing and consequent well-being. I argue therefore that medicine's limited view of humanity supported by simplistic bioethical criteria, have failed to prioritise relationships of care as a means for promoting recovery, or engaging with suffering, pain and to some extent death *in a compassionate and deeply meaningful way.*

Research Findings

Medicine exists to fight death and disease.[740] Such a stark reality leads I believe to the urgency with which the demand for organs is regarded. The persistently high ratio of those needing transplants compared with those willing to donate, works against medicine's prime reason for existence and precipitates the kinds of discussions, debates and initiatives either to overcome problems associated with donation or to promote methods to encourage more individuals to donate. Research into diverse textual sources reveals a plethora of academic papers and tomes that address the strengths and weaknesses of ownership of the body, trafficking and transplant tourism, payment and altruistic donation, and methods of consent. Merely tackling the problems of scarcity feeds into those arguments. Therefore it isn't surprising that many issues remain unresolved, because the reasons for the shortfall in donations are far more complex and interrelated than the piecemeal manner in which those topics have been developed and discussed.

Due attention to the areas that have been examined, I felt, might shed some light on the difficulties that an alternative bioethical approach would need to take into account. Legalising ownership for instance has been put forward in order to offset the possibility for misuse of bodily materials for the purposes of financial gain and the global issue of trafficking and transplant tourism. A person's control over what is done to her body, or its parts, is important to her psychological development and wellbeing, therefore some kind of legal recognition could purportedly be helpful. Ownership is considered to deal with ethical impasses concerning the lack of bodily materials. Significantly the potential to 'invariably fuel more and more extreme means of dealing with the deficit...' remains an issue.[741] In particular it affects those donors in resource poor settings who are least likely to benefit from medical care pre- and post-surgery. The question lies in whether we 'own' the body in the sense of a material/saleable possession or whether God is the ultimate 'owner', or indeed whether we are stewards of the body for the state, at least from a health perspective. The jury is still out on ownership however.

Payment for organs continues to be illegal in the UK. Certain bioethicists view payment for goods and services in general as routine, and question why the sale of organs should be treated any differently from the selling of any product. Arguments against the selling of

[740] Gawande, A., (2014)
[741] Price, D., (2009*)*

organs on the open market globally underpin the difficulty in pricing strategies that would account for variations in legal policy in different jurisdictions; for the type of organ and variability in organ quality; in overcoming black market dealing and transplant tourism. Doubts remain concerning moral justification for any system of payment that favours those who could pay above all others. Nonetheless the moral conundrum rests in the trade-off between the effects of illegal payment for organs and a legal system of ownership that might lessen global trafficking and transplant tourism.[742]

The lack of organs for transplant results in difficulties particularly associated with obdurate and out-dated policy directives. Firstly the insistence on altruistic and anonymous donation and gift giving is a historical position that does not support current facts and practices. For a number of years directed donation has outnumbered anonymous, altruistic donation in the UK leading to questions over altruism's viability. Given the difficulty of establishing altruism as a concept, I would question whether insistence on it is useful. And anonymity falls into a similar category. Both are overtaken by events. The fact that directed donation occurs more frequently and statistics show on average that fewer than one hundred altruistic donations have been recorded for the last five years or more, lends support to my view. Detaching the insistence on altruism from the notion of charitable gift-giving would reduce the anguish for those ethical organisations attempting to put in place acceptable incentives for the donor that presently are fundamentally sidelining bioethical policy.

Whether it is fair and acceptable for living donors to be financially recompensed for loss of time at work and miscellaneous expenses during the run up to donation, is moot. But breaching anonymity seems justifiable since recipients are able to send letters of thanks to the donor or their relatives that could be emotionally significant to the healing of all those who have been involved. However, incentives to promote donors a higher place on the transplant list for instance, or some form of payment for funeral expenses, would be morally questionable since those who do not donate could be disadvantaged. Any form of payment in kind sends out mixed messages.[743] Incentivisation schemes generally promote the intense focus on the need for organs rather than supporting the donor or the relatives in cases of deceased donation in what is a highly complex decision to donate in the first place. Some kind of 'carrot dangling' I would suggest is ethically inappropriate. It doesn't add to the idea that people may regard organ donation as simply a 'good' thing to do or not.

[742] Radcliffe Richards, J., (2012) Sells, R., (1990) and Price, D., (2009)
[743] See Nuffield's ladder of acceptable remuneration and incentives in Ch.4 p94 of this study.

There is a further but more pressing concern however. The sanctioning of presumed consent is being progressed in Britain after many years of deliberation despite statistical evidence from Wales showing a *marked shortfall* in the annual donation figures, since they introduced opting-out legally in 2015.[744] Yet the figures for those needing transplant in Wales between 2015 and 2017 increased. Although the evidence is still early years, nevertheless the bill to write presumed consent into law in Britain is going ahead. It will affect us all. The British government's firm belief that many lives could be saved annually by moving to an opt-out scheme appears therefore to override current evidence within the UK. Opting-out or presumed consent has been criticised for the removal of autonomy and thus individual control over life.[745] It runs counter to the principle of protecting patients' rights to fully informed agreement, and it could be argued that it clashes with the prevailing practice to involve patients fully in treatment decisions. Indeed lack of agency is potentially part of the very reason why individuals in the UK either do not wish to donate after death, or more likely do not think of doing so - whilst believing organ donation to be worthy; each year some forty per cent of relatives refuse to give permission for donation after the death of their loved ones. NHSBT have suggested certain procedures that will offset such a high refusal rate and have highlighted areas where relatives have given reasons for refusal to permit donation after the death of their relative. I would argue that there are more profound reasons for refusal that surely require further research and would test whether presumed consent is considered ethically sound or not by the general population.

The substantive conclusion from arguments associated with payment, altruism and presumed consent demonstrates the need to disentangle moral arguments from theological or significantly political and out-dated historically nuanced debates. It is critical if recommendations are to progress with reliability and confidence that all sides of any discussion have been fully examined and more importantly are not unduly influenced either by policy precedence or political intervention.[746] Such life-changing ethical decisions require a variety of voices to be heard in order to account for the interests of those who are likely to benefit or not from decisions made on their behalf. Most assuredly at the very least, the input from the experiences of organ recipients, live donors and relatives is vital, and should be openly debated in issues that directly affect them.

[744] Recall in Ch.3 that Wales anticipated a 25% increase in donation. See note 252 p86 in this study.
[745] Price, D., (2009)
[746] An obvious example is the lack of an option in the car licence application form to refuse donation altogether.

My claim that ethical systems require criteria that reflect the body as fluid, porous and replete with meaning, led me to examine Beauchamp and Childress's contention that their Principlist model achieves that purpose. Given my understanding of the nature of the body together with feminist views of multiplicity, compassion and caring, my perspective is incompatible with the Principlist model in many ways. In praxis the Principlist model is considered deficient. Its reputation as a simple 'tick-in-the-box' exercise 'to be gone through' by medical professionals turns out to be a mere process to confirm that procedures have been followed appropriately according to prevailing legal and professional statutes. Whilst being 'attractive' to medical professionals for its simplicity I believe this misses the point and leaves the patient vulnerable to complex decisions in which they have been afforded limited input. The distance that exists between the intellectual aspirations of a high level ethical model that purportedly underpins medical praxis and the everyday ideals of individual's perceptions of goodness/morality is too great to be practicable.

It is difficult to countenance Beauchamp and Childress's intransigence over the inclusion of personhood within their framework, and its link with 'common morality'. Enough evidence from diverse sources has confirmed that perception and affect are closely interrelated in informing our everyday lives and choices. Utilitarian values integral to the Principlist model result in a consequential loss of individual agency for the patient in general.[747] Not to speak of a huge loss of information about the patient and their needs. And claims to any kind of universal application do not hold up in the medical specialisms of donation and transplantation. Autonomy has little part to play where choice for recipients rests on whether to approve surgery or not, in the organ recipient's case choice is virtually irrelevant and informed choice is so complex that having to rely on professional recommendation risks paternalism - the very problem autonomy and informed consent were set in place to overcome. In a climate of advanced biotechnology and a fluid interpretation of the body informed consent 'cannot and should not, aim to be fully specific, or fully explicit.'[748] Aiming for a communicative transaction between doctor and patient is central in recording patient need a prominent place in any medical consent, including permission for organ acquisition or transfer in live or deceased donation, since it has implications for the future care of all concerned in the process.

[747] Komesaroff, P A., (1995)
[748] Manson, N C., & O'Neill, O., (2007)

The criteria of non-maleficence and beneficence are basically not only covered by the law but are also integral to the propositions within the Hippocratic Oath, or more often to the standards set by individual medical organisations. Equally, different patients have different views about what constitutes a harm or a benefit rendering it difficult to defend principles that are considered objectively independent of the patient's judgement. Moreover, doing 'good' and 'doing no harm' are hard to uphold in medical environments where routine invasions of the body exist, often in harmful ways, in the guise of 'doing good.' Whilst necessary to the medical task, non-maleficence and beneficence appear to add little to the power and applicability of the overall framework in protecting patients from malpractice but rather would support the medical profession in instances where mistakes have been made.

Patient need is most assuredly undercut in issues of justice in questions of receiving an organ. Justice sits very awkwardly in the Principlist framework as it impacts on autonomy rather than being integral to it. Hence decision-making in allocating an organ/s is problematic. Whilst finance is naturally a consideration, it is troubling that the tools for guiding decisions to transplant sit more readily in a business environment. Applying risk assessment or quality of life years to decision-making not only introduces bias and injustice by excluding those who don't fit into the suitability category but rather favours those who are perceived as having potentially a long and useful/productive life, whatever that may mean. Such criteria frequently rule out the elderly, very young children, smokers, drug users, and in some cases recovering cancer sufferers for example. Paradoxically however, in the case where presumed consent is written into law, these people will have their organs removed unless they declare otherwise. Thus *quid pro quo* remains questionable.

Fairness and equality are fragile criteria on which to base life changing, life-saving decisions. Justice sits beyond the remit of the individual medical professional who has limited control over what counts as a virtuous/valuable life and moreover limited control over the allocation of financial resources. For patients, loss of agency is significant when decisions go against their expectations of a transplant. Much evidence exists of the feelings of hopelessness and dislocation when transplant is not viable or delayed. The disappointment and dismay together compound both the patient and their relatives' suffering and in serious cases lead to the prospective recipient's death, a death that might have been avoided through an understanding of the patient's wider needs and the placing of practical interim care.

Nevertheless, despite vociferous criticism from a variety of sources, Principlism has proven itself by its sheer longevity. Not surprisingly no other comprehensive method or indeed model has been forthcoming as Gillon has confirmed.[749] In this vein one might ask whether anybody would want to attempt an alternative of such magnitude. But this is the point. Ethics is context driven, messy and imprecise and moral codes become questionable as adequate to the task of engaging and dealing with moral activity. Principlism it has to be said however does, in a limited way prop up the medical professional in circumstances when litigation becomes inevitable. Interestingly, it also supports research proposals as Sharp has discovered.[750] In contrast, the central aim of a bioethical model or approach I believe should be to undergird the life-critical decisions medical professionals have to make all the while assuring the well being of the patient. To be fair it's a difficult ask.

Taking into account the criticisms levelled at Principlism I decided that a complete departure from it and any bioethical criteria that might resemble the prescriptive, static models developed as alternatives, was necessary. Access to the source of suffering I believed would prove helpful. Key for the patient is to be encouraged to hold on to the person they are, to not lose sight of embodied presence, to embrace illness and make sense of it, and to move forward differently but positively within the limits that chronic disease might bring. In my experience, caring involves the skills of listening, touch and intense observation as paramount in offering the patient space for healing to occur. Research confirmed that narrative and dialogue are foundational to an approach to caring and to a caring environment that enables patients to begin the process of self-healing and reconnection as a well and wholistically balanced person.

The lack of pertinent information about the *patient as a person* rather than the role she takes on in the hospital environment - a role confirmed only by clinical case notes and histories - is problematic. Narrative is a means to overcome such a limited role.[751] Maintaining the continuity of the *person*, rather than the temporary role of the *patient*, is critical. Narrative fulfils this purpose. In the process of storytelling the formation of the self is reaffirmed, thus in the flow of the story the self evolves and becomes differently. Rather than being stuck in the world of pain and suffering the creative process of storytelling enables life for both the medical professional and the patient to move on through reflection on ongoing experience. Narrative of what illness means to patients lends weight to my

[749] See note 25 pp16
[750] Sharp, L., (2014)
[751] Frank, A W., (2002,2009,2013) and Charon, R., (2006)

proposition that medical professionals would benefit their patients in the longer term by focusing greater attention on accessing the 'hidden' elements of pain as the root cause of disease.

In transforming the medical meeting into a dialogue rather than the traditional monologue of expert advice, the process of storytelling reveals what 'good' might mean to each interlocutor and how this impacts on their everyday lives and choices. The outcome ultimately underpins the future care needs of the patient. The challenge is to recognise that not only each participant in the dialogue must be afforded 'full legitimacy' in reaching workable solutions but their *values* should be respected too.[752] Recognition of the vulnerability of the other engenders compassion and empathy necessary to heal suffering, and limits paternalistic notions of authority as 'doctor knows best.'[753] Recognition of patients as people is essential, otherwise patients become nothing but their illness, become faceless. Facelessness has been shown to lead to lack of trust and increased hopelessness.[754] Thus *what* we think counts for ethical consideration depends on *how* it is represented. Conscientious sorting out of personal experience, partly through the construction of narrative, I believe is a means to better understanding the moral dimensions of medical care. Caring and relating are deeply resonant, and responding and listening have been shown to be key to bioethics. Thus bioethics is transformed into an *activity* that not only takes account of the variation in context but like the body, is always in a state of flux, always becoming.[755] An ethical approach to care is one that stresses a compassionate response to each patient given her unique needs and desires. Care strengthens sustainable and flourishing relations, not merely survivalist or instrumental ones. It is a wide concept that includes everything that we do to maintain, continue and repair our world and all within. A world in which we share a responsibility to 'interweave everything in a complex, life sustaining web.'[756]

It is self evident that medicine is on the threshold of mega change, since sophisticated technology is shifting the nature of medical praxis in myriad ways. Progress in organ donation and transplantation alone brings into sharp relief the very idea that a transformation in the way the body is to be understood or even valued is already underway. There is a pressing obligation to think seriously about the ethical challenges such progress

[752] See p113 of this study.
[753] Levinas, E., (1988)
[754] See p174 of this study.
[755] Smith, R L., (2001)
[756] Tronto, J., (1993)

will bring. And we need a method for so doing. The idea that we are becoming posthuman ethical subjects in our multiple capacities for relations both human and non-human is a valuable heuristic. As the blurring of boundaries between fleshy existence and biotechnology evolves, the meaning we attach to bodily becoming will have wide-ranging repercussions, and will be keenly felt. Careful examination of those lines of human/non-human demarcation I believe will open out contentious debates about the nature of matter implicating biotechnological progress and necessitating a significant recasting of subjectivity and hence bioethics. As technology advances and transplantation procedures become even more sophisticated, such debates will surely render Principlism unsustainable as a meaningful model for future bioethical guidance.

What might a bioethical alternative look like?

Creation of a framework of criteria that risks once more being treated as a list of measures to be gone through by medical professionals would be retrograde. However, I am mindful of the necessity at least to suggest areas for more consideration. I propose therefore two interconnected strands: a deeper appreciation of compassion, empathy, relationality and responsiveness accessed by the process of narrative as emotionally interrelated with caring for both the medical professional and the patient; and in praxis wholistic, egalitarian, co-creative and co-operative treatment. Together I believe they will offer a more robust alternative and represent the means to 'bioethics in action.'

In practical terms the key lies in transforming medical meetings into a dialogue that will powerfully enhance clinical decision-making.[757] Evidence has shown that narrative medicine builds trust in the process of listening. A deeper level of understanding is reached from the surfacing of significant material through storytelling that might otherwise have taken multiple visits to expose.[758] By the same token, compassion and empathy are engendered by not finalising the patient - cutting their story short or not engaging with their narrative because it doesn't fit for some reason - but rather listening to their story however difficult and time-consuming that may be. Both experience and research have reinforced the notion that the progression of patient's disease gives rise to alterations in physical *and* emotional states, arguments that indicate the need for continuity of medical treatment particularly in chronic illness. Thus the importance of regular meetings with the *same medical*

[757] Charon, R., (2006)
[758] And by that I mean any narrative approach – story, poetry, painting, music might be included here.

professional/team is vital in order to maintain effective intercommunication that will not only involve the patient at a deeper level of interrelationship but will inform with greater clarity any ensuing decisions around medical treatment and follow-up care.

Limitations of the study

The major criticisms of this study will be levelled at the idealistic manner in which I have put forward an alternative approach that I firmly believe resonates with the findings of the Francis Report as discussed in Chapter 6. Those who have commented on my research have already voiced thoughts on how my proposals might well play out, particularly in terms of finance, and the management of resources. Pushing boundaries however is imperative for introducing change that will keep pace with current progress. With luck it propels people into thinking differently and provokes action of a different kind.

The National Health Service is already under extreme pressure to fulfil its purpose through measures to cut costs all the while providing a high level of free access to care at the point of delivery. The trade-off between the business end of medical care and response to the needs of the individual patient as person I am suggesting will prove difficult in the short-term. Limitations aside however, medical progress is advancing apace and whilst this is a blessing in one sense, it has important implications for issues of personal responsibility that will require teasing out. It may be that a form of Hippocratic Oath will be considered mandatory in the future, as certain responsibilities for care are devolved to the individual patient and accountability for treatment is rendered unclear when monitoring of health through medical technology installed in the home increases.[759] This will impact upon any bioethical model already in existence and any model developed in the future. Changes to the tissue laws are inevitable. The challenge will be in careful management to prevent paternalistic anomalies from creeping in.[760] As greater technological control over health monitoring becomes established in the longer term, the prospect that this will free up time for the medical professional in general to offer a more flexible approach to healing and care than hitherto *is realistic*.

[759] See note 23 p15 of this study.
[760] See Gere, C., & Parry, B., in note 207.

Contribution of the study

This study is unique in establishing an alternative view of the body that resonates deeply with the interrelationship of narrative and care in providing a robust, integrated ethical approach. It will enhance medical caregivers' recognition of the complexity of treatment decisions and enable them to deal with everyday ethical dilemmas with greater clarity. In direct contrast to the static Principlist model, it is an approach that I believe will be flexible and fluid enough to encompass the changing needs that new technologies will bring. It focuses attention away from the vicissitudes of a dualist interpretation of humanity, and from historical, legal and political opinion that have long worked against change, to a position that serves, I hope, to confirm the patient at the forefront of medical care. Moreover, in so doing such an alternative approach I believe rekindles much needed trust and faith in medical processes to the benefit of medical professionals as well as patients, enabling everyone to move forward to heal and flourish.

That said the purpose of this study was to create an alternative space in which to contemplate what a change in ethical approach to patient-centred healthcare might look like. However, the impending watershed of further technological progress in ever more sophisticated methods to preserve life, will transform the myriad ways in which medicine is delivered. The blurring of science and nature will require a different approach to bioethics, so that the need to develop ethical norms and values that reflect a fluid view of humanity and morality 'worthy of the complexity of our times,' will be even more pressing. This will entail further research as technological progress plays out. The proposed approach contributes to the way forward and is flexible in seamlessly allowing for future enhancements. Its value lies in prompting future bioethicists to resist looking back to static interpretations of morality that eschew the inexchangeable individual and risk underplaying the nature of the body, as fluid, wholistic, meaningful and relational.

Directions for future research

The ethics underpinning posthumanity is a very exciting area for future research. The potential undoing of the traditionally conceived nature of humanity is imperative for coming to terms with the future in new fundamental ways. This will mean the posing of vital questions in all aspects of life in general, but in medicine in particular.

Areas for future research that could prove worthwhile, include: the management of biotechnology in medicine and research; investigation of the ethical norms and values of organisations who develop and manufacture prostheses and robotics; an ethnographic study into the effect on care that advanced technology will engender, and a further study into the means to garner authentic patient views on its effects through future communities of care, and how those views will be disseminated; the training of all medical professionals in narrative medicine and appropriate counselling techniques leading to a revision of the medical curriculum; and finally research into the kinds of bio/ethical approaches that will be necessary to prevent forms of post/humanity from falling into the trap of gendered norms that will create universal imbalance and risk becoming inhuman(e).

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Appendices

Types of transplant[761]

Autograft

Autografts are the transplant of tissue to the same person. Sometimes this is done with surplus tissue, tissue that can regenerate, or tissues more desperately needed elsewhere. Examples include skin grafts, or vein extraction. Sometimes an autograft is performed to remove the tissue and then treat it or the person before returning it, such as stem cell autografting and storing blood in advance of surgery.

Allograft and allotransplantation

An allograft is a transplant of an organ or tissue between two genetically non-identical members of the same species. Most human tissue and organ transplants are allografts. Further medical intervention in the form of immunosuppressants is needed in allografting to prevent organ rejection.

Isograft

A subset of allografts in which organs or tissues are transplanted from a donor to a genetically identical recipient (such as an identical twin). Isografts are differentiated from other types of transplants, while they are anatomically identical to allografts, they do not trigger an immune response.

Xenograft and xenotransplantation

A transplant of organs or tissue from one species to another. An example is porcine heart valve transplant, which is quite common and successful. However, xenotransplantion is often considered an extremely risky type of transplant because of the increased chance of non-compatibility, rejection, and disease carried in the tissues of porcine or bovine donors.

Split transplants

Sometimes a deceased-donor organ, usually a liver, may be divided between two recipients, especially an adult and a child. This is not usually a preferred option because the transplantation of a whole organ is more successful.

Domino transplants

In patients with conditions such as cystic fibrosis where both lungs need to be replaced, it is a technically easier operation with a higher rate of success to replace both the heart and lungs of the recipient with those of the donor. As the recipient's original heart is usually healthy, it can then be transplanted into a second recipient in need of a heart transplant.

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[761] Information for this appendix is taken from various sources: www.en.wikipedia.org/wiki/Organ_transplantation, NHSBT organ donation and transplantation website.

Another example of this situation occurs with a special form of liver transplant in which the recipient suffers from a disease where the liver slowly produces a protein that damages other organs. The recipient's liver can then be transplanted into an older patient for whom the effects of the disease will not necessarily contribute significantly to mortality.

This term also refers to a series of living donor transplants in which one donor donates to the highest recipient on the waiting list and the transplant centre uses that donation to facilitate multiple transplants. These transplants are otherwise impossible due to blood type or antibody barriers to transplantation. The 'Good Samaritan' kidney is transplanted into one of the other recipients, whose donor in turn donates his or her kidney to an unrelated recipient. Depending on the patients on the waiting list, this has sometimes been repeated for up to six pairs, with the final donor donating to the patient at the top of the list. This method allows all organ recipients to get a transplant even if their living donor is not a match to them. In February 2012, the last link in a record 60-person domino chain of 30 kidney transplants was completed in the USA.

Paired and pooled transplants

Donor-recipient pairs who are incompatible by antigen type or blood group and are unable to donate directly are registered in a national scheme to achieve compatible transplants with other pairs. When two pairs are involved this is termed paired donation. When more than two pairs are involved this is termed pooled donation

ABO-incompatible transplants

Because very young children who are generally under 12 months, but often as old as 24 months do not have a well-developed immune system, it is possible for them to receive organs from otherwise incompatible donors. This is known as ABO-incompatible transplantation. Graft survival and patient mortality is approximately the same between incompatible (ABOi) and ABO-compatible (ABOc) recipients. While focus has been on infant heart transplants, the principles generally apply to other forms of solid organ transplantation.

Limited success has been achieved in ABO-incompatible heart transplants in adults, though this requires that the adult recipients have low levels of anti-A or anti-B antibodies. Kidney transplantation is more successful, with similar long-term graft survival rates to ABOc transplants.

Transplantation in Obese Individuals

Until recently, patients labelled as obese were not considered appropriate candidates for renal transplantation. In 2009, the physicians at the University of Illinois Medical Centre performed the first robotic kidney transplantation in an obese recipient and have continued to transplant patients with Body Mass Index (BMI)'s over 35 using robotic surgery. As of January 2014, over 100 patients that would otherwise be turned down at other transplant centres because of their weight have successfully been transplanted.

Major organs and tissues transplanted[762]

Thoracic organs

Heart	deceased donor only
Lung	deceased donor and living-related lung transplantation
Heart Lung	deceased donor and domino transplant

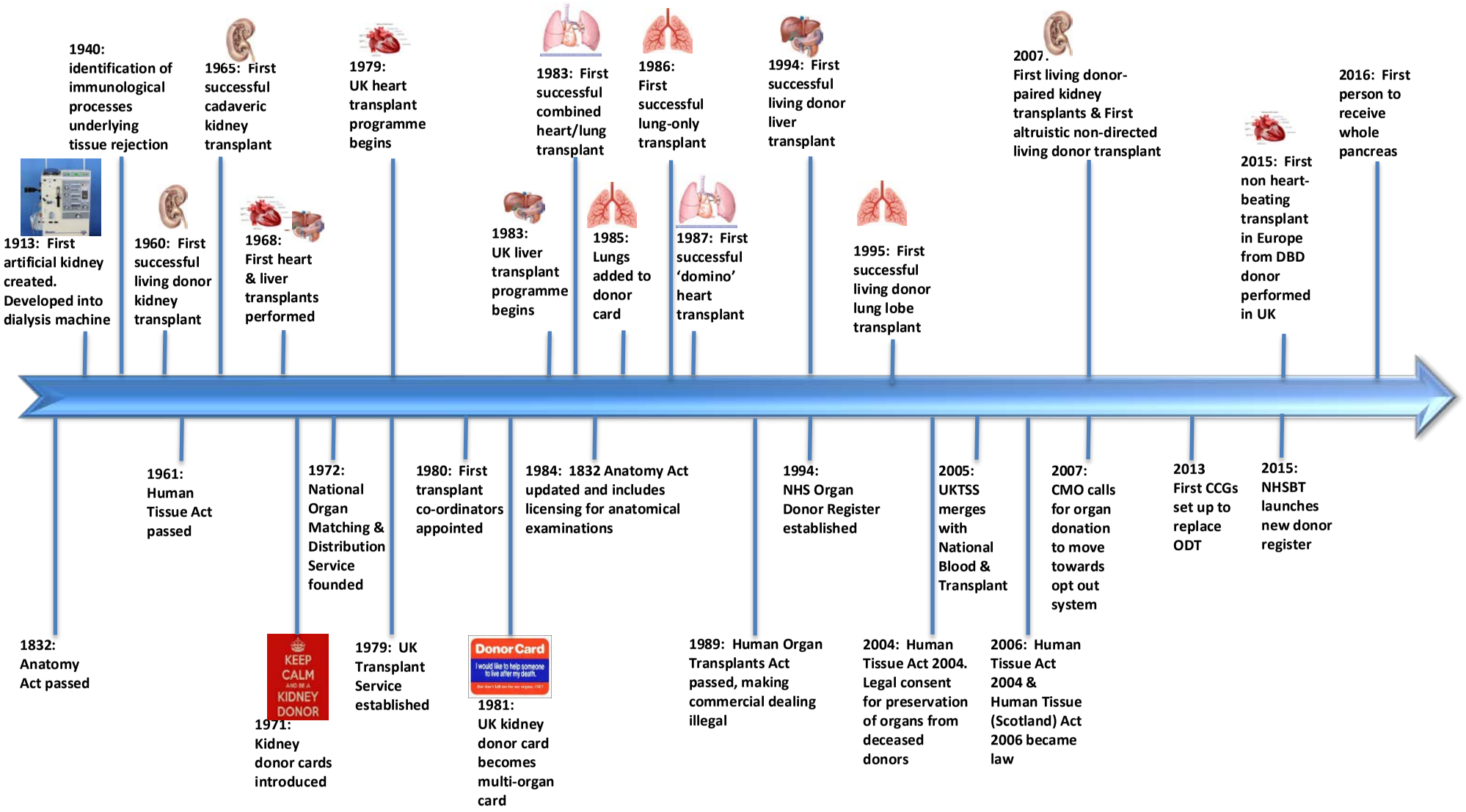
Abdominal organs

Kidney	deceased donor and living donor
Liver	deceased donor and living donor
Pancreas	deceased donor only
Intestine	deceased donor and living-donor
Stomach	deceased donor only

Tissues, cells, fluids (for interest)

Hand	deceased donor only
Cornea	deceased donor only
Skin/face replant	autograft
Islets of Langerhans	pancreas islet cells, deceased donor and living donor
Bone marrow/ stem cell	living donor and autograft
Blood/Blood Parts transfusion	living donor and autograft
Blood Vessels	autograft and deceased donor
Heart Valve	deceased donor, living donor and xenograft
Bone	deceased donor and living donor

[762] www.en.wikipedia.org/wiki/Organ_transplantation



Timeline of key dates in UK donation and transplantation activity